Step By Step

A Resource Guide For Coordinators Of In-home Respite Care Programs For Clients Suffering From Alzheimer's Disease And Related Disorders

A SPECIAL PROJECT OF:
SENIOR CARE
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For editorial assistance, special thanks are extended to Daniel Liebman and Harold Sheffe.

Finally, appreciation is extended to the President, the Board of Directors, executive and staff of Senior Care for their support.

J.E. Maser

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Preface

This Resource Guide for coordinators of in-home respite care programs for the cognitively impaired has been written to assist in the training of careworkers. It is both a curriculum guide and one part of a comprehensive training program. It has been designed as a companion document to **Basic Principles: A Careguide For Careworkers Providing In-home Care To Clients Suffering From Alzheimer's Disease And Related Disorders.**

Information is presented on Alzheimer's Disease, on its effect on the client and the family, and on the ensuing implications for care. A problem-solving approach is used to provide the flexibility required to meet the unpredictable situations that can arise in care. Case examples and assessment tools are included.

Every attempt has been made to prepare the coordinator and the careworker to meet the unpredictable challenges of care. The strategic role of the careworker in ensuring the safety and well-being of cognitively impaired individuals, and in helping them remain at home, is emphasized throughout.

Although it is suggested that this Resource Guide be used by the coordinator in directed group training sessions, it may be provided to careworkers who wish to supplement the information presented in **Basic Principles.**

The principles outlined in this Resource Guide reflect current practice. Hopefully, as more is known about this devastating disease, more specific therapies will become available to manage, control, or prevent it.

To simplify the writing process, and in recognition of the fact that the majority of careworkers and supervisors are female, the feminine pronoun (she, her) is used.

This Resource Guide was funded by a grant awarded to Senior Care, a non-profit multi-service home support agency in Metropolitan Toronto, by the Ministry of Community and Social Services, Province of Ontario, Toronto Area Office, Services to Seniors.

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Senior Care

INDEPENDENCE
FOR THE ELDERLY

November, 1989

A Message From Senior Care

On behalf of Senior Care, I am pleased to introduce two documents:

Basic Principles - A Careguide For Careworkers

and

Step By Step - A Resource Guide For Coordinators Of In-home Respite Care Programs.

Senior Care is a multi-service agency that has been serving community-dwelling elderly for 17 years. Over the past few years the agency has been able to develop its services for caregivers of persons with cognitive impairment. In developing programs for this complex area of need, we recognized a requirement for straightforward, helpful information for caregivers and professional coordinators of programs serving this population. Subsequently, we undertook to produce both **Basic Principles** and the **Resource Guide.**

The Board of Senior Care deserves special mention for their encouragement of this effort, as does the Ontario Ministry of Community and Social Services, Toronto Area Office, — in particular, Brenda M. Elias, Manager, Services to Seniors, and Rhona Phillips, Area Supervisor.

Special mention should go to Senior Care staff: Jerry Berman, Director of Home Services; Joyce Fleiser, Director of Special Services; and Linda Hill, Senior Program Coordinator. Their work laid the foundation for this effort, and their understanding of the issues in caregiving and program organization was extremely valuable.

For editorial assistance, special thanks are extended to Daniel Liebman and Harold Sheffe.

Any project of this magnitude represents the collective thinking and involvement of many different people and organizations. Senior Care wishes to express its gratitude to all of those associated with this effort. We are especially pleased to have had the opportunity to produce material to assist the caregiver and to enhance understanding for serving the client with cognitive impairment.

Michael F. Scheinert
Executive Director

Senior Care is the operating name for Community Services to Jewish Elderly

An Affiliate of the Toronto Jewish Congress

United Way
A United Way Member Agency

Support the Senior Care Foundation.

Part I

Introduction

Chapter 1
Introduction

Aging is a gradual process that involves slowing and decline in physical capacity and function. It is normal, occurs in all living things, and begins at birth. Aging is an inevitable occurrence and not reversible. No two individuals age in the same way, and the rate of aging varies from person to person.

Normal aging is not a disease. Its onset and progression may, however, be influenced by external factors, including:

- lifestyles and habits (smoking, drinking, stress, exercise, diet, etc.);
- environmental pollution (air, water);
- accidents, injuries;
- major life losses (death of a close family member, job loss); or
- acute or chronic illness or disability.

The Well-Elderly

The losses accompanied by normal aging are, in most cases, easily compensated for by the individual. The majority of elderly continue to live independently in the community, with only moderate change in their lifestyle. Most chronic (long-lasting) illnesses and disabilities of the elderly are readily controlled by the use of prescribed medications, diets, or assistive devices (eyeglasses, hearing aids, canes) that the individual learns to manage under the supervision of a physician. Some individuals require occasional assistance with shopping, transportation, or other household chores.

The majority of the elderly are considered and consider themselves to be well. They continue to be active and are able to live independently in the community. The "well-elderly" are able to adjust to and make adaptations for the normal age changes, including the chronic illnesses and physical disabilities that often accompany old age.

The incidence of chronic illness and disability increases with age. Heart disease, arthritic and rheumatic diseases, and cancer are more common in the elderly, and these conditions often require both medical intervention and some assistance with the activities of daily life.

Increasing Number Of Elderly

The number of individuals over age 65 and the proportion of the Canadian population they represent have been increasing steadily over the last quarter-century. In 1931, approximately 6 percent of the Canadian population was over age 65. By 1986 that percentage had risen to 11 percent. It is forecast that by the year 2021, 20 percent of Canadians will be over age 65. The largest increases are occurring in those over age 85.

What This Means

More people are living longer. Although most adapt successfully to the usual age changes, the amount and type of assistance required increase with age and disability. With the increased number of elderly, there is and will be an increased need for assistance by people experiencing difficulties.

It is the stated preference of the majority of elderly to be able to continue living independently in their own homes. Institutionalization is looked upon as a last resort, both by the elderly and by the family.

For the frail elderly to remain safely at home, the availability of in-home support services is necessary. Although the family provides most of the care required by the elderly, as the demands of care increase and the pressures on time and resources mount, the family will require additional help.

Resource Guide

This Resource Guide is concerned with cognitive loss in the elderly. Cognitive loss is not a normal part of aging. It is the result of a disease process or injury. About half of all cases of cognitive impairment in the elderly are due to Alzheimer's Disease. Alzheimer's Disease strikes late in life, affecting the function of the brain. Afflicted individuals gradually lose the ability to function independently and require constant care and supervision to ensure their safety and well-being. It is a devastating disease to the individual and the family.

This Resource Guide is intended to be used by the coordinator as one of the tools to assist in the specialized training of in-home careworkers serving clients suffering from Alzheimer's Disease and related cognitive disorders.

Contents

This Resource Guide reviews the topics important for the careworker to know in caring for the client with Alzheimer's Disease. The guide begins with a discussion of normal age changes; then discusses dementia, Alzheimer's Disease, and related disorders; and then looks at the impact of the disease on the client and the family. It then presents the skills, techniques, and special considerations helpful in providing the appropriate care to the client.

Individualized Approach

Every person, of course, is different, and so too the manifestation and course of Alzheimer's Disease will vary from client to client. An individualized approach, tailored to the client, is required. Management guidelines, reflecting current medical practice, are presented for the common aspects of the disease. As more becomes known about this complex disorder, treatment and management will, it is hoped, become more definitive.

Chapter 2
Respite Care

Individuals suffering from Alzheimer's Disease require increasing amounts of care and supervision, most of which is provided in the home by the family. The family caregiver needs a "break" periodically from the often burdensome responsibility of providing ongoing care.

Respite care, the provision of short-term relief to family caregivers, is a vital service to families of individuals suffering from Alzheimer's Disease. Respite enables the family to continue its supportive role and to fulfil the wish of having their relative remain at home.

The respite careworker plays a strategic role in the provision of in-home respite care. The careworker's role is a responsible one that, although highly challenging, unfortunately is not always given the recognition it merits.

The usual range of tasks performed by the respite careworker for the client include:

- companionship;
- socialization and recreation;
- personal care (bathing, grooming, dressing, feeding, toileting);
- accompanying the client to appointments;
- homemaking/housekeeping (meal preparation, light chores);
- supervision; and
- safe custodial care.

The Respite Care Program

Goal

The goals of in-home respite care programs for the cognitively impaired are:

1) To provide relief to the usual family caregiver.

2) To provide quality physical, social, and emotional care and supervision to the client. Such care and supervision will assist the client to continue to live to his/her potential; to preserve his/her dignity; and, where possible, to enhance the quality of life.

The Respite Careworker

Caring for a client who is cognitively impaired is a challenging experience that requires patience, understanding, and a genuine concern for the individual.

The respite careworker is a special person whose blend of characteristics enables her to meet the demands of care.*

Characteristics Of A Respite Careworker

The following qualities and skills describe the professional careworker.

Personal Qualities

- responsible and reliable;
- caring, compassionate, gentle;
- dedicated, committed;
- understanding, empathetic;
- patient, tolerant;
- flexible, resourceful;
- calm, in control;
- sense of humor.

Personal Skills

- perceptive, aware of client's needs, feelings, and capabilities;
- observant;
- able to communicate;
- able to problem-solve.

Knowledge

- general knowledge of in-home client care procedures;
- willingness to learn;
- knowledge of normal age changes, cognitive impairment.

* For ease of readability, the female pronoun is used as a reference to the respite careworker and the family careprovider. Of course, these roles are filled by both women and men.

Chapter 3
Normal Age Changes

Knowledge of normal age changes is important for several reasons. It allows the careworker:

- to gain an understanding of what the client is/may be experiencing;
- to anticipate the type of problems the client may encounter;
- to be prepared to make allowances for those changes;
- to provide the appropriate support and assistance;
- to be able to recognize normal age changes and distinguish them from signs of illnesses that require medical attention; and
- to gain an understanding of the reason for the suggested care guidelines.

With aging, gradual changes occur. The changes may be classified as:

1) physical or biological,

2) emotional and social, and

3) cognitive (intellectual).

Physical Or Biological Changes

Biological changes are those physical changes that gradually occur in all body processes over the lifespan. Common visible physical changes include: gray hair, wrinkled skin, and stooped posture.

Changes in appearance, while noticeable, are relatively minor in importance to the individual's well-being. The changes that affect the body's internal functioning are more serious and often require special therapeutic intervention.

Slowing Down

A general slowing down usually accompanies aging. The rate and degree of slowing is variable and depends on many factors. Some internal body processes may be slower (for example, rate of digestion) and may be less efficient (for example, kidney function). Reaction times (reflexes) are slower, and the individual may require more time to carry out physical and intellectual tasks; for example, he/she may move more slowly and take longer to solve a problem.

Sensory Changes

The sensory perceptions of the elderly change. The elderly experience a decrease in the accuity of their sight, hearing, sense of smell, sense of taste, and sensitivity to touch. These sensory losses may place the individual at risk. Failure to smell smoke or hear a warning bell can be life-threatening.

Table 3-1 shows the common sensory changes that occur with normal aging and the corresponding corrective or preventive measures that can be taken to ensure client safety.

Table 3-1

Sensory Changes With Age

Sensory Change	Careworker's Response
Sight — decreased ability to: • see fine print or detail; • judge difference in depth (e.g., on stairs); • differentiate between colors; • distinguish light from darkness; • change focus from near to far.	• provide adequate lighting; • color code edge of stairs; • give large-print material; • ensure corrective eyeglasses are worn.
Hearing — decreased ability to: • hear high-pitched tones; • distinguish between sounds.	• ensure client uses prescribed hearing devices at all times; • speak slowly and distinctly; • do not raise the tone of your voice when raising the volume; • face the individual when speaking to him/her; • ask the client to repeat your message; • avoid unnecessary background noise.

Sensory Change	Careworker's Response
Smell, Taste — decreased ability to smell and taste, which may lead to: • loss of appetite; • excessive use of salt and sugar; • inability to detect spoiled food.	• monitor intake of food and liquid to ensure appropriate consumption; • give consideration to presentation and texture of food.
Touch, Feel — decreased ability to: • feel changes in temperature, making the individual vulnerable to burns or freezing; • sense pressure or pain, allowing injuries to go untreated.	• check room and water temperatures; • observe for signs of skin wounds.

Significance Of Decreased Sensory Perception

Although the elderly person does not sense temperature or pain readily, that does not mean he/she will not suffer from burns or freezing.

Because the perception of pain is decreased, the elderly individual may have a serious illness or injury for some time before it is detected and treated.

Other Biological Age Changes

Other biological changes that occur in the elderly, along with some useful interventions, are listed in Table 3-2 on page 10.

Combined Losses

Many of the conditions listed in Tables 3-1 and 3-2 may co-exist in the individual. Combined, their effects can be extremely dangerous to an elderly person, especially in the presence of illness or other disability. For example, an elderly individual with a sensory impairment may take longer to perceive the smell of smoke, may be unable to move quickly enough to escape the fire when he/she detects it, and may trip and fall, breaking bones while attempting to leave a smoky room.

Careworker's Response

It is important that the careworker be able to recognize the usual age changes, allowing her to:

1) Alert the family and the coordinator to changes in the client, so that the appropriate medical assistance can be obtained. (**Note:** follow-up investigation and action are the responsibilities of the coordinator and the family.)
2) Understand the importance of ensuring compliance with prescribed therapies and routines designed to adapt to and compensate for normal age changes.

Table 3-2

Biological Changes With Age

System	Careworker's Response
Bones and Muscles: • decrease in muscle tone, strength, and endurance; • loss of calcium in bones (at risk of fractures); • problems with coordination and flexibility.	• ensure the use of prescribed assistive devices (canes, walkers, grab bars, etc.); • keep the environment clear of clutter; remove throw rugs or fasten them securely; • encourage compliance with prescribed exercises, stretching routines; • protect from falls.
Digestive System: • digestion is slowed and less efficient.	• provide smaller, more frequent meals; • ensure the use of dentures, if required; • follow prescribed diets; • ensure adequate fluid and fibre intake.
Urinary Tract: • decreased muscle tone and elasticity, may have less warning of or control over voiding; • incomplete emptying of bladder, increasing potential for infection.	• ensure adequate fluid intake; • encourage toileting at regular intervals (every 2 hours to prevent an accident); • recommend a medical assessment for bladder problems (most can be treated).
General Function: • decrease in energy, takes longer to recognize and respond to signals and initiate movements.	• allow sufficient time, do not rush or overwhelm.

Illness

As noted, the incidence of chronic illness and disability increases with age. The elderly are more likely to suffer from heart disease, arthritis, cancer, diabetes, and other ailments than are the young. The elderly individual has to contend with illness and disability in addition to the normal age changes. Some normal age changes become more pronounced in some disease states.

Emotional And Social Changes

With aging comes many life changes. Some are beneficial, others represent losses. It is often difficult for the individual to cope emotionally with the personal and social losses that come with age. Personal and social losses may include loss of independence, function, role, and status. Specific types of losses include:

- changed body appearance (wrinkles, gray hair);
- slowing down, difficulty doing what one used to do easily;
- loss of job (retirement);
- reduction of income;
- loss of health and status;
- loss of friends and family through death; and
- the approach of the end of one's life.

Not unexpectedly, these losses trigger a variety of emotional reactions. Some individuals experience grief, sadness, anger, anxiety, or depression; others are able to accept and adapt to the changes with ease.

Our "youth-oriented" society and the negative social image of the elderly sometimes make these losses harder to bear.

Negative Stereotypes About The Elderly

It is important to take some time to consider the negative social image that afflicts the elderly. The negative image is based on incorrect assumptions that reflect the ignorance and fears about growing older. Unfortunately, even some of the elderly believe these myths.

Some of the common "myths" about the elderly include: "old people are senile"; "old people are all alike"; and "old people can't learn new things."

Cognitive Changes

Cognitive abilities, also known as intellectual or mental abilities, refer to the processes that involve thinking, understanding, memory, judgment, reasoning, and perceiving.

As they age, normal, healthy individuals experience only minor changes in cognitive function. Those usual, benign changes are easily compensated for by the individual.

The primary age-related cognitive change is one of rate. A generalized slowing of cognitive and body processes occurs with age. Despite the slowing, the elderly are still able to accomplish intellectual tasks as they did previously; it just might take them a little longer to do so.

Some intellectual functions improve with age. General knowledge and vocabulary accumulate over time. Creativity can also expand with age.

Cognitive Losses

Cognitive losses, such as memory loss, confusion, and disorientation, are *not* normal aging changes. Transient incidents of memory loss, confusion, and disorientation can occur at any age and may be due to a variety of causes. Some of the causes of transient or episodic cognitive loss include: physical illnesses, injury, emotional upset, boredom, disinterest, or being "preoccupied" with other concerns.

Persistent cognitive losses in the elderly are usually due to a disease or injury, and are considered to be serious.

An example of benign memory loss would be forgetting where one put one's glasses. Forgetting that one wore glasses would be a sign of serious memory impairment.

Successful Aging

Successful aging comes from a combination of factors beginning at birth. Physical and mental health, financial security, comfortable and safe housing, a positive social environment, a healthy life-style, good eating habits, a balance of work, exercise, and leisure activities, and caring and supportive family and friends are the basic ingredients for successful living and aging.

Coping well and living successfully at all ages also involves:

- the ability to adapt to and cope with change;
- remaining physically and mentally active;
- continuing to be involved with people and activities;
- learning to accept and make the most of one's strengths and limitations; and
- maintaining a positive, realistic attitude to life.

Self-care is an essential component of successful living. It is the responsibility of each of us to build the foundation for our own and our family's successful aging.

Summary

It is important for the careworker to be familiar with normal age changes in order to:

- have a better understanding of what the individual is experiencing;
- be alert for age changes or other signs that may indicate the presence of illness or injury and require medical attention; and
- help the client cope better by making allowances for normal age changes through ensuring that assistive devices are used or prescribed therapies are followed, and by providing the appropriate type and level of assistance.

The balance of this Resource Guide focuses on one disorder that may affect elderly individuals: dementia, as typified by Alzheimer's Disease.

Chapter 4
Dementia

Dementia, a medical term often misunderstood and misused, describes a set of symptoms with diverse causes and a variable course. The symptoms include memory loss, confusion, loss of intellectual and physical functioning, and personality change. In dementia these symptoms interfere with the individual's ability to function and reflect a change from the person's previous level of function.

The Person With Dementia

Signs of dementia include:

- progressive decline in intellectual ability;
- loss of memory for recent events;
- confusion, disorientation to time, place, and person;
- difficulty thinking and problem-solving;
- impaired judgment;
- difficulty understanding and learning new information; and
- difficulty communicating.

Dementia can also involve changes in the individual's personality, mood, and behavior. Dementia can interfere with work, social life, and family life.

Cognitive Impairment

Many of the symptoms of dementia are related to problems with thinking, or "cognition," and are called cognitive impairments. Cognitive (intellectual or mental) impairment refers to the loss of ability to control one's thought processes and actions, and the inability to function independently. Throughout this Resource Guide, the term cognitive impairment will be used interchangeably with Alzheimer's Disease.

Dementia is not a normal part of aging. Most people live to a very old age without experiencing the symptoms outlined above.

Types Of Dementia

Reversible Dementia

Many illnesses and some injuries cause dementia-like symptoms. Some of the illnesses and injuries can be treated or cured. In such cases the dementia is said to be reversible because the symptoms go away when the underlying cause is treated.

Causes Of Reversible Dementia

Malnutrition, severe vitamin or hormone deficiency, infections, depression, brain injury, liver or kidney disease, and adverse reactions to certain drugs are some conditions that may cause dementia-type symptoms. When these conditions are detected early enough and treated, the symptoms may be partially or completely reversed. For this reason it is very important that the individual with such symptoms receive a thorough medical assessment and appropriate treatment.

Irreversible Dementia

When an illness or injury destroys brain tissue, the damage is permanent and the dementia is not reversible. This condition is known as irreversible dementia; it cannot be cured and is ultimately fatal.

Causes Of Irreversible Dementia

Irreversible (permanent) dementia occurs when there is damage to and destruction of brain tissue. More than half the cases of irreversible dementia in individuals over age 65 are caused by Alzheimer's Disease.

Stroke is the second leading cause of irreversible dementia. Strokes occur when the brain is suddenly deprived of its normal blood supply. Without an adequate blood supply, brain tissue dies. Other causes of irreversible dementia in the elderly are Parkinson's Disease and Korsakoff's Syndrome.

In this Resource Guide we will be concerned specifically with dementia of the Alzheimer's type. Many of the techniques and suggestions presented in this guide are helpful for dementias of any cause.

Chapter 5
Alzheimer's Disease

Alzheimer's Disease is a progressive, degenerative brain disease. Its manifestation reflects a change from the person's usual condition. It begins with mild forgetfulness and confusion that worsen, interfering with usual daily life functioning. The course of the disease is not predictable. Cognitive and physical impairments become increasingly severe and ultimately result in death.

The rate of progress of Alzheimer's Disease is variable; it may progress very slowly or very rapidly. No two individuals will experience the disease in exactly the same way.

Who Gets Alzheimer's Disease?

Alzheimer's Disease can strike anyone, regardless of sex, race, education, or economic or social status. It occurs rarely in middle age. The incidence is about 5 percent at age 65, and it rises sharply, affecting approximately 25 percent of the population over age 85.

Cause Of Alzheimer's Disease

The cause of Alzheimer's Disease is not known at this time. There are a number of theories being investigated. There is no known cure at this time. Alzheimer's Disease is not known to be contagious.

Diagnosis

Diagnosis is usually based on the symptoms, the clinical history, a mental status examination, and physical and laboratory investigations. A number of special tests can be done to rule out treatable causes of dementia and to measure and monitor the cognitive function of the individual. Confirmation of the diagnosis of Alzheimer's Disease requires the examination of a sample of the brain tissue. Alzheimer's Disease is characterized by specific changes in brain tissue.

Brain Changes

In Alzheimer's Disease:

1) the brain shrinks in size, or atrophies;
2) the inner spaces in the brain enlarge, forming cavities or spaces;
3) nerve structures change and deteriorate, so they do not function properly ("neurofibrillary degeneration"); and
4) clusters of degenerating nerve endings accumulate ("senile plaque formation").

Functions That Are Preserved

In early stages of the disease, affected individuals appear normal. Social skills remain intact long after the disease progresses. The individual's physical appearance, strength, and health remain good for some time. The individual's emotional capacity remains (although altered), even when the dementia is quite severe. Affected individuals are able to sense the perceived feelings of others and can respond to them on an emotional level.

Course Of Alzheimer's Disease

The development and progression of the symptoms of Alzheimer's Disease vary from individual to individual and are extremely unpredictable. Nevertheless, the symptoms often present themselves in the following pattern:

1) memory loss for recent events;

2) conceptualization problems (difficulty putting things together);

3) visual/perceptual problems;

4) language difficulties;

5) emotional or personality changes;

6) difficulty with motor coordination (for example, walking).

Although some apparently lost functions may return for a time, the regained function is only temporary and the loss is ultimately permanent.

Stages Of Alzheimer's Disease

The symptoms and progress of Alzheimer's Disease are usually described according to stages. The length of time in any one stage varies from person to person.

As the disease progresses, the individual's emotional reaction changes. In early stages, the individual experiences frustration and fear as he/she has the awareness that something is wrong. One client described it as though his "brain was not working right." In later stages, cumulative cognitive losses, including loss of awareness, blunt the individual's negative reaction — having the effect of "shielding" him/her from what has happened, and often restoring a calmness. While this response indicates the client's condition has worsened markedly, at least the client does not appear to be as distressed. Throughout this progressive condition the client continues to perceive, on an emotional level, the acceptance or rejection of those caring for him/her.

Alzheimer's Disease is usually described in three stages:

1) early — mild impairment;

2) middle — moderate impairment; and

3) late — severe impairment.

Table 5-1 shows the stages of Alzheimer's Disease and the symptoms associated with each stage.

Table 5-1

Alzheimer's Disease, Stages And Symptoms

Stage	Symptoms
Early/Mild	• memory loss for recent events; • disorientation to time and place (gets lost); • increasing difficulty handling complex tasks (such as paying bills); • may experience mood swings; • requires little or no assistance to function.
Middle/Moderate	• marked increase in forgetfulness; • difficulty concentrating or following a conversation; • increase in disorientation to time, place, person; • failure to understand the meaning of what is going on around him/her (e.g., does not recognize what is seen or heard); • difficulty making choices or decisions; • difficulty performing tasks, activities, and purposeful movements; • requires simple instructions, repeated frequently; • problems with coordination and movement (may have difficulty walking, writing); • appears self-absorbed and insensitive to others; • may experience mood swings: is agitated, paces, wanders, or withdraws; • requires assistance and supervision.

Stage	Symptoms
Late/Severe	• no apparent memory (recent or past); • complete disorientation, does not know who they are or where they are, does not recognize others; • difficulty with all purposeful movements, including eating, walking; • unable to communicate; • incontinent of bladder and bowel; • requires 24-hour supervision.

Intellectual Awareness

The individual's reaction to the illness varies with the progress of the disease, and so do his/her needs. Table 5-2 summarizes the changes that occur as Alzheimer's Disease progresses.

Table 5-2

Stages Of Alzheimer's Disease And Individual Awareness

Stage	Individual's Awareness/Needs
Early/Mild	• usually aware there is a problem; • concerned with memory problems and other difficulties; • some clients will try to hide the problem, and may make reminder lists to help them; • some clients will blame others for their difficulties, and will make up excuses; • needs little assistance.
Middle/Moderate	• awareness of difficulties is much less, but disability is much greater; • may be anxious and restless, or withdrawn; • still has emotional sensitivity; • requires assistance with personal tasks of daily living; • requires supervision for safety.
Late/Severe	• completely dependent; • requires 24-hour supervision and assistance; • appears to be completely unaware.

Emotional Impact

Cognitive losses not unexpectedly affect the individual's emotional state and behavior. Emotional reactions may be expressed in many different ways. How an individual reacts depends on many factors, including his/her basic personality: what the person was like before the illness.

Some individuals will become anxious, fearful, angry, hostile, or belligerent in the early stages, when they are aware of their losses and difficulties and feel they are losing control over life. Memory problems make some individuals suspicious and paranoid, and they think others are stealing from them or intentionally doing things to confuse them. Feeling lost and disoriented causes some clients to become restless, and to pace and wander, as though looking for something.

As the disease progresses and awareness, insight, and memory decrease, the anxiety decreases as well. Many clients become self-absorbed, withdrawn, and quiet. Some may be disruptive, continually calling out words or sounds. Others may wander off, and still others appear as if in a daze.

Effect Of Disease On The Family

Alzheimer's Disease has a profound effect on the family. The anguish of seeing a family member undergo such catastrophic changes is a major source of stress.

The family experiences a great sense of loss and grief as they helplessly watch their relative deteriorate and change from the person they once knew. As the family anticipates further losses and changes, feelings of frustration, powerlessness, fear, guilt, and depression are common.

The overwhelming demands of care often mean that the family caregiver often neglects her own health, suffering physical and mental exhaustion as she gives up a personal life to provide care.

As the client becomes increasingly dependent, the roles of the family members change.

As the disease progresses, the client becomes increasingly unavailable emotionally to the rest of the family. The loss of the client's ability to relate on an emotional level is another stress source to the family members.

Caregiving becomes a 24-hour-a-day job, seven days a week. The responsibilities can become overwhelming, leading to exhaustion for the caregiver.

The family caregiver needs help to provide care to the relative and to maintain her own emotional and physical health. The family caregiver is sometimes referred to as the "hidden victim" of Alzheimer's Disease.

Careworker's Role

The client's and family's emotional response to the disease process will affect their relationship with the careworker. To be able to provide effective, compassionate care, the careworker must be sensitive to the losses, changes, and feelings experienced by the family as well as by the client.

Summary

Alzheimer's Disease is a progressive, fatal disease for which there is no known cause or treatment. It is devastating to the individual and the family. As the disease progresses, the client is increasingly dependent on others.

Although the suggestions presented in this guide and in BASIC PRINCIPLES have been found helpful in client care, it is not possible to anticipate all occurrences, and unexpected problem situations do arise with clients. It is important that you let the careworker know that Alzheimer's Disease manifests in unpredictable ways, and that it is sometimes difficult to manage some client situations. Be sure to stress that if such difficulties arise, it is not because the careworker is poorly skilled but because of the unpredictable nature of the disease. Encourage the careworker to persevere through trying times. This area will be dealt with more fully in Chapter 17, Behavior.

Chapter 6
The Individual With Alzheimer's Disease

No matter how cognitively impaired, the individual with Alzheimer's Disease is still an adult human being. The cognitively impaired individual has feelings and needs like every one of us, and has the right to be treated with dignity and respect.

It is important throughout life to consider the feelings and needs of every person, despite the level of impairment. The individual's feelings and needs may change during the course of the disease, but they always remain important.

This chapter is intended to help sensitize the careworker to the client's feelings and needs, and to introduce the basic guidelines for providing good client care.

Feelings

Feelings remain intact long after dementia is advanced. Feelings are expressed and interpreted through words, tone of voice, facial expression, and behavior.

People with Alzheimer's Disease are highly sensitive to the feelings of those around them. If they sense anger, impatience, or disgust in others, they become upset. Similarly, they are calmed and reassured when they sense the warmth, caring, and acceptance of others.

Careworker's Response

It is important for the careworker to:

1) be aware of and sensitive to the client's feelings, and acknowledge them;

2) learn to recognize and control her own feelings that may be expressed indirectly; and

3) accept and respect the client's feelings without judging or denying them.

The careworker can achieve these objectives using the following guidelines.

Guidelines For The Careworker

Be Aware Of The Client's Feelings

To find out what the client may be feeling or experiencing, look for clues in his/her:

- facial expression, gestures;
- mood;
- tone of voice; and
- actions or behavior.

Acknowledge The Client's Feelings

Let the client know you recognize and respect his/her feelings by stating them directly. For example, if you see the client sitting quietly, eyes downcast and heavy, you may say: "I see from your eyes that you are sad." Acknowledging their feelings lets clients know that they are understood; confirms their sense of worth and dignity; instils in them feelings of safety and security; and helps build a trusting relationship.

Use Your Own Sensitivity

Use your natural sensitivity to reach out to the client. Your caring, interest, and compassion will help you to tune in to the client's and the family's feelings, and to respond to them appropriately.

Individual Differences

Feelings differ from person to person, and they change within an individual through the course of the disease. Because the feelings and experiences of the individual are so important, the following section is included to expand on the client's experience of the disease. The two tables in the previous chapter should also be reviewed.

Individual's Feelings Through The Course Of The Disease

Early/Mild Stage: Forgetfulness And Memory Loss

In the early stage, most clients are aware that something is wrong. Confusion, disorientation, and memory loss make life difficult for them.

Most clients in the early stage have some awareness of their losses and difficulties, and often feel anxious, angry, frightened, or depressed. Feelings of uselessness and worthlessness are common.

Middle/Moderate Stage: Unable To Function On Own

As the cognitive losses increase, the client gradually loses the awareness that something is wrong. Feelings of anxiety, agitation, and restlessness may be seen in behaviors such as wandering, hostility, or belligerence. Some clients may become passive, withdrawn, and quiet. Verbal communication declines steadily. Feelings continue to be expressed through actions, mood, and appearance. Most clients continue to respond to others on an emotional level, showing a sensitivity to the feelings expressed by others verbally and nonverbally (through tone of voice, facial expression, touch).

It is usually in the middle stage that careworkers are called in to provide assistance.

Late/Severe Stage: Requires Constant Care And Supervision

In the late stage, most clients are bedridden and appear unaware of their surroundings. It is not known if clients understand anything going on around them. Most clients continue to be sensitive to the emotional expression of those around them. A calm and reassuring manner has a settling effect; anger, hostility, frustration, and disgust are upsetting.

Because there is a possibility that, on some level, clients do understand, and because they are sensitive to the feelings of others, it should be assumed that clients do understand. Every effort should be made to continue to communicate and act with clients as if their words and actions are understood. This approach is part of providing humane care and ensuring that dignity and quality of life are maintained.

At this stage, many clients require institutional care.

Social Skills

The social skills — how we learn to get along with others — remain intact long after cognitive impairment is advanced. An individual suffering from Alzheimer's Disease will remember how to greet a stranger appropriately long after he/she has forgotten how to do up a button.

Often clients will continue to behave differently with their family than with others, including the careworker. (We are socially conditioned to act one way with family, another way with friends, strangers, or colleagues.)

It is important for the careworker to reinforce the client's social skills. The retained social skills make life seem more normal, and are reassuring to both the client and the family.

Different Perceptions

Often, there is a discrepancy between the client's perception that something is wrong and the family's observations. Some clients are able to hide a problem from the family, while in other cases the client is unaware that there is a problem but the family knows that something is wrong.

Needs

Regardless of age, sex, ethnic background, education, financial means, health (physical, mental, or emotional), all people have the same basic needs.

These needs are grouped into two categories: physical and psychological.

Physical needs reflect the necessities of life: adequate food, water, shelter, and safety. These basics must be satisfied for life to continue.

Psychological needs are our emotional and social needs and include: security; affection (kindness, companionship, involvement with others); a sense of purpose and achievement (feeling useful, needed, important); a sense of control over one's life; and a sense of fulfilment.

Careworker's Role

It is important that the careworker is aware of the physical and psychological needs of the client. She should have an awareness of the ability of the client to achieve those needs independently. As well, the careworker should understand how, in providing care, she can help the client meet his/her own needs and so achieve quality of life.

Physical Needs

As noted, physical needs are the basic necessities of life. The careworker must first identify those physical needs for which the client requires assistance and then provide the appropriate level of assistance.

The careworker may be required to assist the client with the following activities to ensure that physical needs are met:

- Personal care activities (bathing, grooming, dressing, eating, toileting); and
- care of the home, so that it is safe, clean, and comfortable.

Case Study

Mr. M. is a 71-year-old client who was recently diagnosed as having dementia of the Alzheimer's type. He lives alone. The careworker, recently assigned to provide respite, was concerned about Mr. M.'s eating. Listed below are some of the issues the careworker thought important to check out:

- Is he able to shop for food himself?
- Is he able to select a well-balanced diet?
- Is he able to prepare food?
- Does he remember when it is time to eat?
- Does he eat an appropriate amount of food?
- Can he manage cutlery?
- Can he feed himself?
- Does he chew his food?
- Does he remember to swallow?
- Does he drink enough liquid?
- Are his teeth and mouth in good condition?

Dividing Complex Activities Into Simple Tasks

In considering the client's physical needs and the type of assistance that may be required, it is necessary to divide complex activities into separate tasks, as shown in the case above.

Dividing complex activities into simple one-step tasks helps to identify those parts of the activity the client can still perform independently. It enables the careworker to determine which tasks the client can no longer perform and to identify the required intervention.

Psychological Needs

Fulfilment of the individual's psychological or emotional needs contributes to "quality of life" and provides "life satisfaction." The careworker can help the client meet his/her psychological needs as she assists with the activities related to the physical necessities of life.

For example, safety and security needs are met when clients know they can rely on the careworker to be there, when scheduled, and to provide care that is consistent, familiar, and humane.

Feelings of belonging and involvement develop in clients when they are encouraged to participate in activities, and to be involved in decisions that affect them.

Consideration of the client's psychological or emotional needs are important in all aspects of caring, at all times. Even as the careworker helps the client with intimate, private activities, such as bathing or toileting, it is important to be mindful of the client's needs for privacy and right to dignity and respect.

Careworker Guidelines: Helping Clients Meet Psychological Needs

Doing too much for clients can be as harmful as doing too little. If a client does not have the opportunity to use and practise remaining skills, they will soon be forgotten. The saying "use it or lose it" holds true for the individual with Alzheimer's Disease. Clients feel better about themselves when involved with their own care and with other activities.

It is important that the careworker be able to recognize the client's capabilities and limitations; know when to provide the client with assistance, to prevent frustration and encourage participation and independence; and know what level of assistance is appropriate.

Here are some steps the careworker can take:

1) Divide activities into simple one-step tasks.

2) Adapt and simplify routines and procedures.

3) Modify the surroundings so they are easy for the client to manage. Encourage the family to maintain the surroundings at all times. For example:
   - avoid clutter;
   - keep objects "in their place";
   - remove dangerous or potentially dangerous items (sharp objects, lighters, etc.);
   - ensure adequate lighting;
   - label rooms, drawers, etc.

4) Provide only as much assistance and direction as necessary for the client to carry out the task without experiencing undue frustration. The types of assistance that may be provided (from the least to the most) include:
   - providing written "reminders";
   - providing verbal reminders or clues;
   - setting up in advance the items necessary to perform the task;
   - leading the client to the appropriate area (e.g., to the kitchen, if it is meal time);
   - pointing out or placing in the client's hand the item in question;
   - demonstrating the activity (e.g., act out spooning food from bowl);
   - continuing to provide reminders;
   - getting the client started (e.g., place your hand over the client's and guide the client through the appropppriate motion until he/she is able to take over).

To the extent possible, involve clients in making decisions that affect them. This sense of control can be achieved by allowing a choice between two items. For example, when assisting with dressing, offer the client a choice of two garments: "Do you want to wear your red sweater or your blue jacket?"

Show the client appropriate affection, warmth, and caring. Be a friend and companion. Set aside a time to sit and talk, or share an activity. Let the client know that you value this shared time. Do not show impatience, anger, or disgust with the client. Never argue or reprimand. Clients will not understand, and they will only become more upset.

Remember, the client is an adult. Treat the client with respect and dignity. Use simple language, but do not talk down to clients.

Be supportive. Give "positive" feedback. Reward and encourage client efforts and achievements appropriately. Thanks, touch (hugs, hand-holding), smiles, praise, and treats (food is preferred by most) are good reinforcers.

Be consistent and provide reassurance. The careworker can be the stable, familiar anchor in the client's confusing world. Show the client you are dependable by being on time, coming as scheduled, and helping him/her maintain some control and independence.

Be sensitive to and acknowledge the client's feelings. Respond to the client with kindness, in a caring, gentle way.

Be patient! Showing patience is part of being accepting and supportive. Do not rush the client.

Chapter 7
The Family Of The Client

Family members who look after an ill or disabled relative are referred to as "caregivers." The caregiver is usually the spouse or eldest (adult) child. Most commonly, it is an adult daughter who assumes the primary responsibility for the care of her elderly parent(s). Often the caregiver too is elderly, and may have illnesses, disabilities, and other problems of her own.

Alzheimer's Disease affects the whole family. In this chapter, the effect of Alzheimer's Disease on the client's family will be reviewed.

Feelings

The feelings of family members change when family roles change. When the head of the household in a traditional family becomes ill, some family members may have a very difficult time coping with and accepting that the ill member can no longer assume the leadership role. Family members may become anxious, or even resent the loss of "leadership."

Caregiving can be emotionally and physically demanding. The family of the individual with Alzheimer's Disease is under a great deal of stress. It is difficult to watch someone you love decline, changing radically from the person he/she once was and knowing that there is little hope of recovery. Families grieve at the losses and anticipated losses.

It can be burdensome to provide the 24-hour care and supervision required as the disease progresses. It is often difficult to cope with the unusual behaviors that sometimes accompany cognitive impairment. The emotional well-being as well as the physical health of the caregiver are often jeopardized by the burdens of care. Many caregivers suspend their own careers and social lives to devote their time to providing care.

Family members experience a range of emotions including a sense of loss, grief, sadness, anger, frustration, guilt, and fear. On the positive side, they may also experience the satisfaction of knowing they are doing everything they can for their relative. They treasure the remaining time they have to share, and are grateful for moments when their relative is happy and able to respond to them.

Involving Nonfamily Members

The decision to involve nonfamily members in the care of a relative is difficult for many. Despite the burdens and challenges of caring for an individual with Alzheimer's Disease, the family often resists help from someone outside the family.

Spouses are usually more reluctant to accept help than are adult children or other family members. Healthy spouses in particular are more reluctant to admit a need for, or to accept assistance from, "outsiders."

Reluctance To Accept Help

Families may be reluctant to accept help for a variety of reasons. Most families are very sensitive. Some families:

- feel guilty for having to ask for help (they feel that they "should" be able to manage on their own);
- find it hard to "give up control" of the care;
- feel no one can do as good a job as they can;
- feel it shows they have failed or are not competent to look after their relative;
- don't want to admit the reality of the situation (both their relative's deterioration and their own limitations);
- fear an invasion of their privacy;
- experience financial difficulty in paying for assistance;
- fear theft;
- had previous bad experiences with help;
- have never had help, and don't know what to do or expect;
- often are so overburdened and overinvolved that they lose objectivity and perspective and do not recognize the stress they are experiencing;
- feel they can do "everything" — an often unrealistic expectation that frequently results in burn-out and exhaustion;
- don't want a stranger caring for their relative.

Some families are concerned about the reaction their relative will have to a "stranger" or "outsider" caring for him/her. This worry becomes even more of an issue if the client had placed a high value on his/her independence and privacy, had believed families should sustain themselves, and was the "head" of the family.

Some families may be concerned that a worker, unfamiliar with their relative, will not able to deal with the relative's unusual or unpredictable behavior, understand the relative, anticipate his/her needs, or provide compassionate, dignified care.

Despite the family's fears and concerns, which are very real and must be acknowledged, the family needs the help and support of others to share in the care of the ill relative.

Careworker's Role

The relationship the careworker builds with the family requires special care and attention.

It is important that the careworker understand what the family is going through. This understanding will help her to be supportive and empathetic. Acknowledging the feelings of others, without judging or minimizing their feelings, is an important part of providing emotional support. To be empathetic is different from showing pity.

Being aware of what the family is experiencing is also helpful in understanding the family's behavior and feelings. This understanding is especially important when the family's negative feelings appear to be directed at the careworker. The family members' frustrations, fears, and exhaustion may cause them to appear irritable, short-tempered, or critical. It is important for careworkers to know that in all likelihood the family's negative feelings are not directed at them personally. Most likely the family's negative feelings are caused by stress. The support, competence, sensitivity, and caring shown by the careworker will help the family.

The professional careworker is a valuable source of support and can make a significant contribution to the well-being of both the client and the family.

Summary

The family of the client with Alzheimer's Disease is sometimes referred to as the "hidden victim" of the disease. The family undergoes many changes and experiences a variety of emotions through the course of the illness. The family members, like the client, require support and care for their continued health and well-being.

Part II

The Careworker

Chapter 8
The Careworker

The careworker is clearly in a position to make a vital difference to the health and well-being of the client and the family. In performing this task, the careworker faces many challenges. Although the job description of respite careworker has defined roles and responsibilities, the position requires flexibility. It is part of the careworker's job to be able to adapt to the unique, unpredictable, and changing needs of the client. Many situations require that the careworker make care-related client-management decisions, alone and on the spot, in response to unanticipated situations.

It is essential that the careworker be prepared, to the extent possible, for the types of situations that may be encountered, and that she be provided with guidelines and suggestions on how to manage unexpected situations. Much of this Resource Guide focuses on client-centred aspects of care. This section focuses on issues related on a more personal basis to the careworker.

Preparing The Careworker

Review And Reinforce Careworker Strengths

The careworker's knowledge, skills, experience, personal qualities, and specialized training equip her for the care situation. It is important to emphasize in the training program (and to remind careworkers in follow-ups) that:

- the careworker always has access to her supervisor for direction, assistance, support, or clarification;
- the careworker knows that clients, their home, and their family caregivers are assessed by the coordinator prior to the provision of service;
- the role and expectations of the service are clearly defined and communicated to the family (and client, where feasible); and
- all information relevant to the careworker (e.g., special problems or routines) is communicated to her by the coordinator.

Client's Situation

To prepare the careworker to the extent possible, many of the difficulties that may be encountered are presented in this Resource Guide and in Basic Principles.

It is important that the careworker know that difficult situations are in the minority. Most of the time, life is relatively "normal"; and most clients are pleasant and easily cared for. Most difficult situations occur for a "reason" and can often be avoided or limited by following the principles of care outlined in this training program. In the majority of cases, planning properly, structuring a routine, knowing the client, using commonsense, and maintaining a sense of humor will help make the day go smoothly.

Although in the minority, some difficult and unpredictable situations arise from time to time despite the careproviders' best efforts. The occurrence of such episodes should not reflect negatively on the careworker.

Feedback From The Client Or Family

The client/family may not acknowledge the careworker's efforts as often as one may wish. The coordinator should provide regular feedback to the careworker. It is important that the careworker be secure in her knowledge that the work she is doing is worthwhile and appreciated.

Maintain Objectivity

It is important for the careworker to maintain objectivity in the care situation and to have realistic expectations. Affected clients do not have control over what they say or do, and can unintentionally say or act in a way that is unpleasant or hurtful to the careworker. It is important that the careworker remember that such occurrences are due to the disease: they are not intentional, nor are they personally directed. Maintaining objectivity will help the careworker accept trying episodes if they occur.

Careworker Guidelines

In training the careworker, the coordinator is advised to emphasize the importance of the following guidelines.

Keep appointments as scheduled. Last-minute cancellations and lateness are disruptive to the client and family and cause a breakdown in trusting relationships.

Be compassionate and empathetic. It is important that you recognize the client's needs and are sensitive to the stress that the client experiences. (You are not expected to meet all needs.) Develop a good rapport with client and family.

Follow the routine or instructions of the family. It is important that you respect the client's/family's rights, lifestyle, and possessions, while in their home. Do not try to change their values, beliefs, or lifestyle. If you feel the family needs training to help them care for the client, inform your supervisor. You may refer the family to your supervisor or to their physician if they require counselling or training in the care of the client.

Follow a familiar, consistent routine. Any changes in the client's care routine should be made slowly. Get to know the client and his/her routines. Adapt to the client's lifestyle, level of function, and preferences.

Use your commonsense. If the client is upset and refuses to do something, do not force the issue unless there is a safety problem. Consider the relative importance of the issue. Is it a problem? If so, for whom? What is the worst possible outcome?

Act in a gentle and relaxed manner. Act as you would want someone else to act when caring for you or your close relative. Remember, clients are sensitive to the feelings and moods of those around them.

Be flexible. It is essential that you be able to respond and adapt quickly to sudden changes that can occur in the client or the surroundings.

Be tolerant of yourself as well as of the client and family

Don't get discouraged. Keep trying. Don't give up! The client and family need you and appreciate you.

Do your best.

Six Common Problems

Six problem situations that the careworker may encounter with the family or client are presented to prepare the careworker. In general, these potential problems reflect the emotional reactions experienced by the client and family to the losses and changes. Suggestions are presented to help the careworker manage these relatively common situations.

1. Reluctance Of Family Members To Leave And Allow Careworker To Look After Client

- Give them time. Remember, the client is their close relative; they have suffered many losses. The family member may be overprotective and is experiencing many different emotions. The family member may feel guilty about leaving the relative, even for only a few hours. If the caregiver chooses to stay with you, that is her right.
- Understand what it means to the family to have a "stranger" looking after their close relative.
- Show that you respect and are interested in the well-being of the client and the family.
- Gain trust by being dependable, capable, responsible, and caring.
- Be consistent in your approach with the client.
- Follow the instructions of the family member.
- Be reliable. Show up on time for your shift, and perform your job to the best of your ability.

2. *Dissatisfaction Of Family Member With Work Done By Careworker*

- Do not argue with the family member. Call your supervisor, inform her of the problem, and ask her to clarify your duties and responsibilites.
- If there is a misunderstanding on your part, your supervisor will advise you and assist in resolving the problem (by providing additional training or support).
- If there is a misunderstanding by the family member regarding the services provided, your supervisor will talk to the family member and discuss and clarify the services provided.

3. *Personality Conflict Between Careworker And Family Member*

- Try to resolve conficts at the earliest sign.
- Identify the problem as specifically as you can.
- Try to understand the other person's position.
- Think about how you may have contributed to the "problem."
- Think about other approaches..
- Discuss the situation with the family member and express your concern and desire to resolve the problem.
- Advise your supervisor of the situation.
- If resolution is not possible, a new placement may be the best alternative.

4. *Resistance On Part Of Client: "Go Home, I Don't Need You"*

Try to understand what it must be like for the client who is suffering from cognitive loss. Your presence confirms the reality of the client's losses and worst fears. The confusion and lack of understanding caused by cognitive impairment can make the client suspicious and distrustful of "strangers."

- Go slowly.
- Introduce yourself by name.
- Leave conversations open and general. Speak in simple words and sentences.
- Explain simply and briefly why you are there.
- If you upset the client when you say, "Your wife asked me to come today; she is going shopping," then you may have to say, "I am here to visit." (It is not, however, recommended that you lie to the client. Give only the briefest explanation so that you don't upset the client. Do not confront the client by saying you are there because he/she cannot stay alone.)

5. Overinvolvement On Part Of Careworker

Some cases will be more difficult than others. Certain cases may remind you of someone in your past, such as a parent, grandparent, or spouse, for whom you had and still have strong feelings.

This association can be good or bad. It is good if it helps you better relate to the client. It is bad if it reminds you of a problematic relationship and has an adverse effect on the care you are providing.

Signs of overinvolvement include doing too much or experiencing excessive negative feelings on a particular case.

Doing too much for the client can be as harmful as not doing enough. If the individual is not given the opportunity to use remaining skills, he/she may lose them more quickly. Doing too much also makes the client more dependent and harms his or her self-esteem.

It is important to know that some clients may affect you more than others do. They may remind you of someone else, or they may just be very difficult. Whatever the cause, it is often helpful to try to see the client for who he/she is. You must be able to recognize and resolve your feelings to ensure they do not interfere with the caring process. The supervisor is available to discuss these very normal reactions with you; if necessary, she will reassign the case. Often, discussing your feelings is helpful in clarifying and resolving such situations. Sometimes, the assistance of another trained professional is required.

Remember that client confidentiality does not allow discussing a client or his/her family with others outside the authorized care team.

6. The "Difficult" Client

Sometimes a client will take out his/her bad feelings on you. It is important to understand what the client is experiencing. Imagine how you would feel and act if you did not understand what was going on around you and could no longer look after yourself. In general:

- try to be as patient and supportive as possible;
- act in a calm and relaxed manner;
- follow the suggested care guidelines for managing difficult behavior (Chapter 18);
- remember that the client's difficult behavior is not directed against you personally;
- remember that the behavior will soon pass and be forgotten by the client;
- learn from the situation (identify what may have triggered it and know the "warning" signs);
- know and accept that the behavior is part of the disease and that the client is not able to control his/her words or actions.

Summary

The careworker has a responsible and sometimes difficult job. The careworker can provide vital support in the care and well-being of the client with Alzheimer's Disease.

The special training, experience, knowledge, and skills of the respite careworker enable her to perform this very important role.

Families report that the most helpful and appreciated careworkers are those who are reliable and compassionate, who show caring and respect to the client, and who do their best.

The supervisor is available to the careworker as a resource and for support in dealing with problems and issues arising in the care situation.

Chapter 9
Building Trust

Earning the trust of the client and the family is an ongoing and important task for the careworker. In the absense of a trusting relationship, the careworker will have difficulties fulfilling her duties. For these reasons, the subject of building trust requires emphasis in a training program.

The home situation is a complex one, with client and family burdened by profound losses and challenged by a sometimes overwhelming situation. The careworker enters an often highly emotional environment. The family may have difficulty coping and yet, as we have seen, still may be reluctant to accept the help they need.

Special Trust

The respite careworker is in a position of special trust, being responsible for the safety and well-being of someone no longer able to look after himself/herself.

The Foundation Of Trust

Building trust is an ongoing process. Trust is developed and earned over time through our actions, conduct, and achievements. Many factors contribute to the building of a trusting relationship. Reliability, honesty, and competence form the foundation of a trusting relationship in the respite care situation. Trust will develop as the family observes the skills and manner of the careworker.

Agency's Reputation, Careworker's Reputation

A trusting relationship begins with the reputation of the agency. The agency's reputation in turn comes from the fine job carried out by its professional respite careworkers, whose knowledge, skills, and experience are reflected in their job performance. The performance of each careworker therefore influences the reputation of the other careworkers employed.

Individually, the reputation of the careworker is based on her performance. The special training taken by the careworker is reflected in her confident, capable manner as she performs her duties to the best of her ability. Her knowledge, experience, confidence, and caring are reassuring to the family.

Establishing A Trusting Relationship With The Family

Building trust starts with the careworker's first contact with the family. It is important that the careworker take the time to talk to the family caregiver.

The careworker, when meeting the family caregiver, should briefly discuss her own role, find out about the client, and review emergency procedures. Any misunderstandings should be discussed with the supervisor.

Client

The careworker should find out about the client's routines, abilities, likes, and dislikes. What is likely to upset him/her? How can the situation be avoided or managed? The careworker should find out about special diets, medications, and other needs.

Emergency Procedures

It is the responsibility of the coordinator, who assesses the client and arranges the service contract, to obtain the names and telephone numbers of those who are to be contacted in case of an emergency involving the client. This information must be provided to the careworker.

It is also the responsibility of the coordinator to ensure that the careworker is familiar with the agency's policy and procedures for handling different types of emergency situations in the home.

Building A Trusting Relationship With The Client

The careworker's approach must be tailored to the client's individual and changing needs. Adapting to the client's situation is one important way that the careworker can gain trust. The careworker can promote client trust by:

- being consistent;
- following a predictable routine;
- adapting activities to the client's level of function;
- being aware of the client's needs, comfort level, feelings;
- providing support and reassurance;
- showing patience and acceptance;
- acting in a caring, kind manner;
- acknowledging client accomplishments and efforts;
- treating the client with dignity and respect;
- involving the client in activities and including him/her in decisions;
- avoiding situations that cause client distress;
- resolving problems quickly;
- acting in a calm, confident manner.

Chapter 10
The Team Approach

Alzheimer's Disease is a complex disorder that affects all aspects of the individual's life.

Many types of support and care services are required to meet the diverse needs of the client. As the disease progresses, the individual's needs increase. People with specialized skills are required to provide the care necessary to ensure the client's health, safety, and well-being.

No one person can meet all the client's life needs. A number of people working together, each bringing specialized skills and knowledge, are needed to provide the necessary care.

Team

When a number of people work together on a specific activity, they are referred to as a "team." Each team member has his/her own specialized role or function.

Every member in the team is important. Each team member has a specialized role to play.

Team Manager

As with any team, a coach or manager is required to coordinate all the players to make sure the common goal is achieved.

Team Plan

Every team has a goal and develops a plan to achieve that goal.

Team Approach

The team approach to health care is based on the treatment of the person as a whole. It considers the client's many medical and nonmedical needs of life. Treating the individual as a "whole" is known as the "holistic" approach.

Health Care Team

The health care team is a specialized group of professionals who work together to provide all the client's health care needs. Some of the members of the health care team are physicians, dentists, nurses, pharmacists, social workers, physical and occupational therapists, and nutritionists.

Benefits Of The Team Approach

Just as the client benefits from the team approach, so do the team members. Sharing information and expertise, the team members work together to resolve specific client care problems. As well, support and assistance are available to all team members through their supervisors.

The Team Approach And The Client

Caring at home for the client with Alzheimer's Disease involves the family, the health care team, and the services of a respite care team. The respite careworker is an important member of this expanded team.

The following points should be emphasized by the coordinator in the orientation and training of the careworker.

Team Approach In Respite Care

The team approach is important in the care of an individual with Alzheimer's Disease because client needs are many and varied.

The respite care team enables the client to continue to live at home. Every team member has an important role to play in ensuring that this goal is met and that the client's safety and well-being are top priorities.

Treatment Plan

The team goal in respite care is referred to as the "treatment plan." The treatment plan specifies a plan of action and the role of each member in carrying it out.

The treatment plan has to be assessed, evaluated, and adjusted regularly because the client's condition is always changing. Reports from each team member on the progress of the client are necessary for the manager to know when and how to modify the treatment plan.

Role Of Careworker In Respite Team

The careworker is the nonfamily team member who has the most direct contact with the client. As such, the careworker is in a position to be the first to detect changes in the client's condition. One of the responsibilities of the careworker is to report changes to the supervisor and the family. It is then the responsibility of the supervisor/coordinator to follow up client problems with the family, the team manager, or other professionals, in order to ensure that appropriate help is obtained.

Reporting

The careworker works directly with the client, the family, and the supervisor.

The careworker reports directly to her own supervisor but should also inform the family about changes seen in the client's condition and should share tips with them.

The coordinator is available to the family to provide referral to other resources for themselves and for the client.

Responsibilities Of Careworker

The careworker is required to:

1) Perform tasks to the best of her ability as trained.

2) Observe the client carefully and communicate regularly with her supervisor. It is vital that any sudden changes be reported to the supervisor immediately, so that the appropriate follow-up can be arranged. (Changes can indicate new problems or a worsening of the client's condition. This topic is dealt with more fully in Chapter 12, Observing and Reporting.)

3) Contact her supervisor and request assistance when faced with a situation that is difficult to manage. (As noted, it is the responsibility of the supervisor to follow up.) It is dangerous, irresponsible, and wrong not to ask for help when unable to manage a situation effectively.

Standards Of Behavior And Ethical Responsibilities

All team members are bound by the same general standards of behavior and ethics when caring for a client. At all times all team members must:

1) Respect the dignity, lifestyle, and possessions of the client, and be courteous, pleasant, and considerate to the client and the family.

2) Maintain client confidentiality. Client information is private. A careworker can discuss the client only with her supervisor and anyone authorized by the supervisor and the family. Discussions should be carried out in a private place. If the client is able to understand, he/she should be included in the discussion, if present. Never talk about a client in front of the client unless he/she is included in the discussion.

3) Act in a gentle, caring, supportive, patient, and tolerant manner.

4) Be dependable. This means being on time for appointments and remaining with the client until the agreed-upon time (provided it is safe to leave).

5) Be neat.

6) Perform duties to the best of ability.

7) Call for assistance when unable to manage a situation.

The Respite Team Members

Some of the other key members of the team who may be called in to provide client care are identified to provide the careworker with an understanding of what they do.

Care Manager

The care manager, sometimes called the case manager, acts as leader, receiving and coordinating information from each team member and ensuring that overall decisions are most appropriate for the client.

Physician
The primary role of the physician is to assess, diagnose, and set up a medical management and treatment plan for the client. He/she will often refer to specialty paramedical careproviders (some of whom are listed here) to provide specific services for the client.

Nurse
The nurse, who provides care that is supportive to life, carries out treatments for disease, rehabilitation, and health-preventive measures as prescribed by the physician.

Social Worker
The social worker deals with social and emotional problems associated with changes in the personal life and health of the individual. The social worker's goal is to improve the social functioning of the client and provide information on appropriate community support services.

Psychologist
The psychologist assesses mental status and helps the client and family deal more realistically and effectively with the situation they face.

Pharmacist
The pharmacist provides advice and counselling on the safe and effective use of drugs and drug-related items.

Nutritionist
The nutritionist helps design meal plans and recipes to ensure the client receives a good, well-balanced diet.

Physical Therapist
Physical therapy, physiotherapy, or physical rehabilitation involves the use of exercises or special devices to prevent disability, to restore or maintain physical function, or to provide relief of pain.

Occupational Therapist
The goal of occupational therapy is to make the most of the individual's functional capacity so that he/she can effectively perform the activities or tasks required for self-maintenance in daily living. These tasks are known as "activities of daily living," and are referred to as "ADL."

Speech/Language Pathologist And Audiologist
The speech therapist treats communication disorders involving speech and hearing (audiology). Communication is vital to both self-expression and in socialization. Communication disorders are a source of frustration and a threat to the safety and well-being of the individual.

Homemaker

The homemaker provides care and assistance on a regular basis to help the individual with the essential activities of daily life, including personal care, meal preparation, and housekeeping tasks.

Working Together

The various team members, working with community and volunteer groups, with the client, and with the client's family and friends, all contribute to the care and well-being of the client.

The careworker should be encouraged to communicate with other team members who are present in the home during her shift. At a minimum, the careworker should introduce herself and identify the agency for which she works. It would be helpful if the careworker had the agency's business card with her supervisor's name and telephone number on it to exchange with other team members.

Summary

The respite careworker is an important member of the care team. Each team member works toward the goal of maintaining, and improving where possible, the health and well-being of the client.

Part III

Special Skills

Chapter 11
Problem-Solving And Decision-Making

The problem-solving process involves first finding out what is causing or contributing to a difficult situation, then identifying, deciding on, and taking the appropriate action to resolve or limit its harmful effects.

Decision-making is one of the careworker's key responsibilities. The cognitively impaired client is no longer able to make appropriate decisions and must rely on the careworker's judgment.

A problem-solving approach is used throughout the Resource Guide. The flexibility built into this approach allows the careworker to respond to the unpredictable and often sudden changes that can occur with the cognitively impaired client.

Effective Problem-Solving

Problem-solving uses the knowledge and skills that the careworker has acquired over time through training and experience. The goal of effective problem-solving is to ensure client safety and well-being.

Effective problem-solving benefits the client, the family, and the careworker. Client safety and well-being is the primary concern in any problem-solving or decision-making process.

Effective problem-solving by the careworker can:

- limit or prevent dangerous or unpleasant situations with the client;
- assist the family in coping with similar situations (through the sharing of experiences); and
- improve the careworker's expertise and confidence in caring for clients.

General Guidelines For The Careworker

In any care situation and especially in problem-solving situations, it essential that the careworker:

- consider client safety and well-being of foremost importance;
- act in a calm and relaxed manner when with the client; and
- maintain objectivity.

The careworker should refer regularly to Table 1 in Chapter 6 of BASIC PRINCIPLES ("Basic Steps in Problem-Solving").

A Problem-Solving Approach To Care

Problem-solving is a simple technique that involves:

1) finding out what is causing the problem, and

2) taking the appropriate steps to resolve the problem in a way that will ensure the client's continued safety and well-being.

There are many different approaches to problem-solving, but all involve the same basic steps. Some steps take little time while others, according to the situation, require more thought and time. There is often more than one right way to resolve a problem situation.

Problem-Solving: Basic Steps For The Careworker

1. Identify and describe the problem

Example: Mr. A. appears agitated and anxious, and he is pacing around the room.

2. Observe and analyse the situation

This step involves a careful, systematic review of the client, the immediate surroundings, and your behavior. The purpose is to identify possible factors that may be causing or contributing to the problem. (It is often helpful to try to look at the situation as the client sees it.)

Client

Observe the client's appearance, behavior, and mood; compare it with his usual behavior. Look for clues about the message the client is trying to communicate.

Example: In observing Mr. A. now and knowing his usual condition, you notice the following:

- He is more confused and disoriented than usual and is having more trouble understanding what is going on.
- From his history, you know he has trouble seeing, especially in the dark. Also, he often suffers from constipation. He appears to be straining his eyes, and he is rubbing his stomach.
- Over the past half hour he has become increasingly restless and appears anxious.

Surroundings

Observe the area around Mr. A. Try to see it as he does. Is there a lot of activity going on that could overwhelm him? Are there people there he no longer recognizes and who he may be afraid of? Is the room too hot or too cold? Is there enough light, or are there dark shadows that could be confusing or scaring him?

Example: You note that a neighbor has been visiting Mrs. A. all afternoon. Mrs. A. and the neighbor have been busy talking. Their voices are high-pitched, and the women speak quickly. Mr. A. has been sitting quietly in the same room. It is cloudy outside, and the room is darker than usual.

Careworker

Think about how you have been acting today. Individuals with Alzheimer's Disease are highly sensitive to the mood and behavior of those around them. What nonverbal message could you have been inadvertently giving through your actions or facial expression? Did the client interpret the frown from your headache as disapproval of him? Did you follow the client's usual routine?

Example: This afternoon, you were busy doing some light household chores at Mrs. A.'s request. You did not go for a walk with Mr. A. because he was with his wife and the neighbor. Mrs. A. has been busy with her visitor.

Other Observations

Some problem situations arrive predictably at the same time of day. The late afternoon is often a problem time for those with Alzheimer's Disease. It has been suggested that as the sun goes down, it is increasingly difficult for the individual to see, and the subsequent visual distortions contribute to client agitation and restlessness. Or, perhaps, the client is simply tired. For some clients, the time after waking up in the morning or after a nap is when they are most confused and, consequently, more likely to have difficulty coping.

As you become familiar with the client's daily coping pattern, you will learn to structure the client's routine to accommodate him.

Example: On some occasions when Mr. A. has had a very busy day and there has been a lot of activity going on around him, he has become agitated by late afternoon. For Mr. A.,the neighbor's visit was stressful. He did not recognize her, could not follow the conversation, and missed his usual walk.

3. Propose alternative solutions

Using your observation and analytical skills, think about what factors may likely be causing or contributing to the problem, and what possible steps you may take to resolve or limit them.

Example: For Mr. A., you might consider the following factors that could be contributing to his agitation, restlessness, and pacing:

- confused and disoriented;
- needs to go to the bathroom;
- needs exercise;
- has trouble seeing as the sun goes down;
- is hungry or thirsty;
- is bored;
- is tired.

Careworker's Role

- provide reassurance and reorientation to the surroundings;
- take to the bathroom;
- take for a walk;
- turn on the lights;
- give him a snack;
- involve him in an appropriate activity.

4. Consider the possible actions and select a course of action

Think about the relative merits of the interventions identified above. Based on your evaluation, select those interventions that would make the most sense to try first, second, and so on. This is the "course of action." Solving problems often requires more than one action. Because so little is known about the disease, and because it is so variable and unpredictable, there is no one "right" answer. Often several measures may be required to overcome a problem situation.

Example: You may decide that for Mr. A., the first thing you are going to do is reassure him. Follow the basic principles that you have learned. You may:

- approach Mr. A. from the front to get his attention;
- address him by name and identify yourself, speaking in a calm, gentle voice;
- take his hand to help him focus his attention;
- suggest that he go to the bathroom and provide him with the assistance he needs;
- then, reassess Mr. A. and decide if a walk, rest, or snack would be the best suggestion.

5. Implement the action selected

Now is the time to put the plan into action. A calm and relaxed manner is essential. Remember, it may take several different steps to resolve the problem. You will not know if something will work if you don't try. What works one time may not work another time because the disease effects are so variable and unpredictable. Be alert for the effect of each intervention. Prepare to modify your actions accordingly.

Example: You turn on the lights in the room; you approach Mr. A. from the front, calling out his name to get his attention; and so on. Observing that Mr. A. is much calmer after he goes to the bathroom, you suggest going for a short walk. On return, you settle Mr. A. comfortably in his familiar chair and put on his favorite record as you prepare his supper.

6. Evaluate the action taken

Assess objectively the effect of each action taken. Did the action achieve its goal or purpose? If the action taken was not successful, try your next option. Continue trying and reassessing and re-evaluating until there is satisfactory resolution of the problem.

Was the action chosen successful in solving the problem? What was most helpful? What was least helpful? What would you try next time?

7. Call for help

If unable to resolve the problem, and if the client's health, safety, or well-being is in question, call your supervisor for further instruction. (Follow the Emergency Guidelines of your agency.)

8. Review and discuss the situation and actions taken

After resolving the problem, review the situation and how it was managed. Think about what else may have been helpful and about how future situations might be handled. What did you learn from this episode? What would you do differently the next time?

It may be helpful to discuss the situation with your supervisor, colleagues, or the client's family so that they can learn from your experience.

9. Record the incident

Include in your report an accurate and complete description of the episode. (Review Chapter 7 of BASIC PRINCIPLES.)

Avoiding Or Limiting Problem Situations: Suggestions For The Careworker

Although there is often little that can be done to anticipate problems arising from the disease process, it is frequently possible to limit those situations that arise. If you carefully observe the client and his/her surroundings and monitor your behavior, you may spot early clues or signs of problem situations that can be resolved before they fully develop.

Tips To Help Divert Client's Attention

It is often necessary to divert or redirect the client's attention from upsetting or problem situations before the problem-solving process can be carried out. Because of the client's memory problems, upsetting situations are forgotten as soon as the client is involved in something else. Diversion techniques include:

- giving the client a snack;
- going for a walk;
- involving the client in a favorite activity.

Summary

It is important that the careworker:

1) Act in a calm and relaxed manner.
2) Remove the client and herself from harmful situations.
3) Divert the client's attention from upsetting situations, and distract him/her with acceptable alternate activities
4) Plan in advance. Be alert for warning signals of trouble. Where possible, avoid situations that are likely to result in a problem.
5) Remember that there is no "one right answer" for the unpredictable situations that may arise from the disease process. A variety of measures may have to be tried before finding the one that works.

Chapter 12
Observing And Reporting

Observing

Observation — looking very carefully — is a learned and valuable skill. For those caring for clients with Alzheimer's Disease and related disorders, it is of vital importance.

As noted, clients with Alzheimer's Disease depend on their caregivers to do their observing on their behalf. The caregiver must recognize and notice changes in the client's behavior, mood, appearance, or surroundings that could affect his/her health, safety, or well-being. Observing is an ongoing activity in the care situation.

The careworker spends more time with the client than do any of the other nonfamily team members. Her observations can be crucial in maintaining the health, safety, and well-being of the client.

Changes

Changes, particularly sudden changes in the client's appearance, mood, or behavior, must be investigated. Changes indicate that something is happening within the individual. The change may be in the client's physical, cognitive, or emotional condition. The change may represent a worsening of the disease, or a new illness or injury that may require treatment. The change may be caused by someone or something that is upsetting or frightening the client. Changes that are observed in the client's condition are sometimes referred to as *symptoms*.

Follow-Up

The cause of the change must be investigated. It is the responsibility of the careworker to report changes to her supervisor and to the client's family. The supervisor and the family are then responsible for getting the appropriate medical attention.

Client care routines will have to be modified and adapted to the client's changing level of function. This may be done by the careworker alone or in conjunction with her supervisor, the family, and/or other team members.

In this section, we review the principles of systematically "observing" the client in an unobtrusive manner.

Guidelines For Observing

Client

The client may be experiencing bodily changes. Note the client's:

- appearance, behavior, and mood;
- abilities to understand, think, communicate;
- physical abilities (e.g., ability to use utensils, climb stairs);
- ability to interact with others (recognize family and friends, react to strangers).

Surroundings

People, activities, objects, and conditions may affect the client. Busy, confusing, or overwhelming surroundings can trigger behavior problems. The careworker uses her own senses of sight, hearing, smell, and touch. *Be aware of:*

- room temperature;
- light level;
- background noise;
- furniture layout;
- potential hazards (rugs to slip on, cords to trip over).

Use your eyes. Carefully observe the client's:

- general activity;
- body positioning;
- skin color (including lips and eyes; check for flushing or irritation);
- discharges (from any part of the body; watch for blood, vomiting, etc.);
- open areas, cuts, rashes, swellings, lumps;
- changed facial expression (note also what the client is looking at);
- loss or change of activity level or function;
- change in eating pattern;
- change in sleep habits;
- change in urine/stool.

Use your ears. Listen closely to what the client says and how the client says it. Listen:

- to what is said — the words;
- to the underlying feeling message:
  - the clarity of expression,
  - the tone of voice;

- for the choice of word:
  - are words used correctly?
  - is the client "making up" words?
- for the apparent level of understanding;
- to the client's response to noises and sounds;
- to detect if the client has difficulty hearing;
- for unusual body sounds, coughing, sneezing, breathing difficulties.

Use your nose. Smell to detect unusual odors:

- in the client's body, wounds, breath, urine;
- in the surroundings (stale air, smoke);
- in food (notice if foods have gone bad).

Use touch. Feel the client's skin to detect:

- hot or cold skin temperature;
- if client responds when touched.

Caution

Elderly individuals lose their sensitivity to pain and temperature. The elderly individual may have a serious injury that he/she does not "feel." Just because the individual does not sense an injury does not mean that he/she is not at risk from it.

Investigating The Symptoms

Involve The Client

If the client is able to understand, ask gently about the symptom. The client may be able to tell you something about it (for example, is it a mole he has had all his life?).

If the client is unable to speak, ask him/her to point out to you or to show you what hurts.

Some clients will be able to write their message in words or draw pictures when they can no longer speak well.

Familiarity with normal age changes and the changes that occur with cognitive impairment will help the careworker recognize and distinguish among normal age changes, the disease process, and new conditions.

The Elderly Are At Greater Risk

The following are other points to stress to the careworker.

Chronic illnesses and disabilities are more common in the elderly. The elderly individual is more susceptible to illness and infection than is the younger individual, and takes longer to recuperate. Because sensory perception is lessened, even the well-elderly are less likely to notice warning symptoms, and so the condition may be quite advanced before it is detected.

People with Alzheimer's Disease have much more difficulty adapting to normal age changes than do the well-elderly. Normal age changes compounded with cognitive impairment place the client at even greater risk of having an undetected health problem or injury.

Observations should be carried out in an unobtrusive, nonthreatening manner. Staring at the client, or appearing to "test" the client, may cause anxiety and trigger an emotional outburst or episode of difficult behavior.

The importance of detecting change — comparing what is observed now with what was seen previously. Consider the client's:

- memory;
- mood;
- ability to understand;
- ability to communicate;
- reaction to other people (family, friends, strangers).

A difference in any of these areas means that a change has occurred in the client. The change should be reported to the supervisor and the family.

On detecting a symptom, observe it carefully so you can describe it objectively — reporting exactly what was seen, heard, smelled, or felt.

Reporting

The careworker's observations and reports play an important part in the overall management of the client's well-being. The observations reported are included in the client's record and will be used to monitor the client's progress and to develop his/her personal treatment plan.

The client record has many useful purposes. It provides much valuable information for all the members of the health care team. The record provides an objective account of:

- how the client has changed over time (skills, level of function, etc.);
- rate of progress of the disease (how quickly or slowly the disease is progressing);
- onset of new symptoms, from the disease or from a new illness;
- strategies used to manage problem behaviors; and
- the treatment and therapies used to assist other team members in providing optimal client care.

Recorded Information

Recorded information must be specific, accurate, and complete. The careworker may be the first person to notice a change in the client's condition which indicates something serious that requires attention or special follow-up.

Reports are usually written objectively. Objective reports state exactly what was observed — what was seen, heard, smelled, or felt.

Contents Of The Report

The report should include the following:

- time and date;
- an objective description of what happened or was observed;
- in the case of a behavior, a description of what happened before the behavior started (for example, what the client was doing);
- a description of what was done to manage the situation;
- a description of the client's response or reaction (include also any interventions that were tried and not successful); and
- a notation on whether or not the problem was resolved.

Subjective Reporting

If the careworker wishes to give her opinion about what happened, or why she thinks it happened, she is free to do so. She must, however, state that it is *her opinion.* Giving a personal opinion or thought about something is known as "subjective" reporting.

The careworker's opinion is valuable because she knows the client, and was present. It is important in the report to distinguish between what is reported objectively and what is reported subjectively.

Timing

For the report to be most accurate, it should be written as soon as possible at the end of each shift. The careworker can make notes during the day to help remember important points.

What To Report Immediately

Emergency situations and serious changes must be telephoned immediately to the supervisor. The agency employing the careworker will specify those situations that must be reported at once. A written report must be made of all reports given by phone so there is a permanent record.

A sample report form is shown in the chart at the end of this chapter. Note the information that must be recorded.

Summary

Because clients with Alzheimer's Disease no longer have the ability to understand what is going on around them, or within them, and are no longer able to communicate effectivey, they cannot say when they are injured or unwell. Client discomfort or distress may be revealed through subtle signs, such as a change in appearance, behavior (actions), or mood (emotions). Any change from the client's usual appearance, behavior, or mood may indicate that something is wrong and must be investigated.

Careful observation and reporting by the careworker are of vital importance to ensure the continued health, safety, and well-being of the cognitively impaired client.

Client Record Form

Client name _____

Date of problem/symptom _____ Time _____

Problem/symptom observed _____

_____

_____

_____

Length of problem

How long did it last? _____

Is it a continuing problem? _____

What measures were taken to deal with the problem? _____

_____

_____

_____

What was happening at the time the symptom/problem was observed? What was happening just before that time? _____

_____

_____

_____

What help was obtained? _____

_____

_____

_____

Who has been informed?

Name	Phone Number	Position/Relationship To Client

Additional comments or suggestions _____

_____

_____

_____

Careworker _____

Agency _____

Agency's Phone Number _____

Date _____

Chapter 13
Communication

Communication is the term used to describe how information, ideas, feelings, thoughts, and experiences are transmitted from one person to another. Communication involves at least two people: a sender and a receiver in a two-way process. To be effective, the message must be expressed by the sender and understood, as intended, by the receiver. Communication uses a common language and system of rules to transmit messages. The individual who suffers from cognitive impairment has difficulty handling both parts of the communication process: formulating and sending a message, and receiving and understanding messages.

The Importance Of Communication

Communication is vital to our self-identity and central to our humanness. Without the opportunity to communicate, a person becomes isolated and is likely to experience loneliness and become withdrawn. The individual who is unable to communicate effectively often experiences feelings of frustration and anger.

Types Of Communication

Communication may be expressed verbally, nonverbally, or both ways. Verbal communication uses words that may be spoken or written. Nonverbal communication involves the use of facial expression, tone of voice, gestures, or body language.

Usually both the verbal and nonverbal message are compatible. Sometimes, however, a conflicting tone and verbal message are used deliberately when one is being sarcastic or humorous.

Effect Of Alzheimer's Disease On Communication

In Alzheimer's Disease, parts of the brain are destroyed. This damage prevents the brain from functioning properly and causes a variety of problems, one of which is with communication.

Just as the effects of the disease are slightly different in every person, so too the rate and manner in which communication skills are lost vary from individual to individual.

Even though the communication process is disrupted, the affected individual continues to initiate the sending of messages. Garbled messages, actions, and behaviors represent the person's attempt to communicate. Any attempts to communicate are important and require careful attention by those providing care.

Memory Loss

Because of memory loss, the individual may not be able to remember a message or instruction after it is given. By the end of a conversation, the client may have already forgotten the first part. Some clients forget what they are talking about, even when they initiate the conversation.

Attention Span

Clients with Alzheimer's Disease have difficulty focusing on a subject or maintaining concentration. Their attention span is short because of their memory problems. Such clients are easily distracted and confused by noise, objects, or other activities going on around them. This confusion further adds to their difficulties in focusing and maintaining attention.

Comprehension

The person with Alzheimer's Disease will gradually forget the meaning of words. He/she will have difficulty remembering the names of people and objects and will forget what those names and words represent. As the disease progresses, the client will fail to understand the meaning of a spoken or written message. Even though the client may still be able to speak words, talk in sentences, or even read or write, he/she may be unable to understand the words. This situation can be very frustrating to those providing care. (Note: often the ability to comprehend a written message is retained for a time after comprehension of the spoken word is lost.)

Aphasia

With the worsening of the disease, the individual with Alzheimer's Disease gradually loses the ability to both understand and produce language. This communication problem is known as "aphasia."

The aphasic person may be able to hear, read, or write the word, but the word will have no meaning to him/her. To the aphasic, the word sounds foreign; it would be similar to what we experience when listening to a foreign language.

Maintaining Communication

The ability of the client to communicate will change over the course of the illness. It is very important for the careworker to learn to look for and recognize changes in the client's ability to communicate, and to modify and adapt her communications to the client.

Every client should be encouraged to maintain communication, even when the cognitive impairment is severe. It is the responsibility of the careworker to initiate and assist in communication.

Continued communication with the client is vitally important to the client's well-being and quality of life. Continued communication provides the client the opportunity to have dignified, normal interactions with others.

Communication is a skill. Like other skills, it will be lost if not used. Using this skill may help preserve it a little longer before the disease process destroys it. Some clients seem to appear to decline less rapidly when optimum communication is maintained.

Other Factors Affecting Communication

The client's sight and hearing — both key components of the communication process — can be easily checked by the physician. The careworker should ensure the client is using glasses and hearing aids as prescribed.

Myth About Deafness In The Elderly

One common misunderstanding is that "the elderly are all deaf." It is equally false to assume that the client with cognitive impairment is deaf.

Do not shout or speak in a raised voice to clients unless they have hearing loss. Do not assume the client is deaf. It is annoying to the client who is not deaf to be spoken to in an excessively raised voice.

It is helpful to the elderly individual generally, and to the cognitively impaired specifically, to:

- lower the pitch of the voice (so that it is deeper and less shrill or high); and
- speak at a moderate pace (not too fast and not too slowly).

Communicating With The Alzheimer's Client

Careworker's Role

It takes "two" to communicate, and the careworker assumes responsibility for maintaining communication when the client loses the ability to do so.

To gain insight into the meaning of the client's message, the careworker must be extremely observant. It is important to be alert to changes in the client's ability to communicate and to pick up clues from his/her behavior, body language, tone of voice, mood, or surroundings.

The careworker must also be flexible, able to adapt to and compensate for unpredictable changes in the client's ability to communicate.

For The Careworker — Tips For *Improving* Communication

General

1) Speak slowly, using short, simple words and sentences.

2) Give the client time to take in the message and to reply.

3) Be prepared to repeat instructions or messages.

4) Check out the client's ability to understand the message.

Early/Middle Stages

1) Structure the evironment to make communication easier:

- Simplify the surroundings.
- Eliminate unnecessary background noise (turn off radios, televisions, etc.).
- Remove distracting visual or moving stimuli (such distractions include clutter, extra people or activities that do not involve the client, and even passing traffic, people, or vehicles in the client's visual range).
- Ensure adequate lighting to eliminate shadows and help the client see clearly.

2) As in all situations, act in a calm and relaxed manner:

- Plan (think about what you want to say to the client); then get his/her attention.
- Approach the client from the front so you are easily seen (the client may otherwise be startled by your sudden appearance).
- Position yourself facing the client at his/her eye level.
- Call out the client's name to get his/her attention. Identify yourself by name. It may be helpful to orient him/her to time, place. ("It's Tuesday afternoon. I always come on Tuesday.")
- Take the client's hand(s), or gently touch his/her arm as you speak.
- Speak slowly and clearly in a low tone of voice.
- Make your message simple and clear. Use simple words and sentences.
- Make sure your body language (facial expression, tone of voice, gestures) is compatible with your verbal message. Speak in a calm, reassuring tone. How you speak is as important as what you say. Often a "feeling" message (gentleness, caring, reassurance) gets through long after words are no longer understood.
- Divide long messages into parts. ("After we have lunch, we will walk to the park," is better said as: "First we will eat lunch. Then we will go to the park."
- Pause and wait for a few moments after each sentence to allow time for the client to process your message.
- Repeat your message as often as necessary.
- Demonstrate, through gesture, your verbal message. (If it is mealtime, you can demonstrate by pretending to spoon food from an imaginary plate to your mouth.)

Trouble Seeing Or Hearing

- Make sure the individual is using eye wear or hearing aids as prescribed and that they are in good repair. (If they appear damaged or not functioning, inform the family and your supervisor, who will follow up as appropriate.)
- Eliminate background noises.
- To avoid confusing shadows, be sure the room has adequate lighting.

Short-Term Memory Problems

- Write down important or routine messages.
- In the early stages, the individual may find it helpful to keep a log or memory book to help remind himself/herself.
- A message board that lists the day's schedule or provides other reminders is sometimes helpful. Select one place where messages are kept.
- As the impairment increases, signs labeling important rooms (e.g., toilet) are often helpful.
- Do not expect the client to remember.
- Give directions close to the time that they will be used.
- Repeat. Be prepared to repeat often.
- Do not argue.
- Do not correct wrong words.
- Repeat what you think the client is trying to say.
- Each time you speak to the client, remind him/her who your are. (This is important even in the advanced stages.)

Comprehension Problems

- Keep sentences short; speak slowly.
- Use simple language.
- Allow the client time to understand your message. Do not overwhelm the client with words.
- Enhance the verbal message by pointing out the item/object (coat); initiating the activity (hand client the coat); demonstrating the activity (put on your coat); helping the client get started (help put his/her arm into the sleeve when dressing).
- Make sure your body language is compatible with your verbal message. (Facial expressions, gestures, and tone of voice will transmit a message; sometimes the client will misunderstand both your tone and your words.)

- Be direct. Say what you mean. "Come to the table" will be understood better than "would you like to come to the table?"
- Follow a routine schedule to help the client predict and follow what is happening and (possibly) know what to expect.
- If your verbal message is not understood, write the message simply and clearly or draw a picture and show it to the client. As noted, cognitively impaired individuals often are able to understand a written message or drawing when they are no longer able to understand a spoken message.

Problems With Client's Expression

- Assume all attempts to communicate are genuine. Watch for nonverbal clues. Is the client looking for something? What was he/she doing immediately prior to speaking to you?
- Use your problem-solving skills to investigate and rule out potential physical needs (hunger, thirst, need to go to the bathroom).
- Ask the client to repeat.
- Guess at the meaning, using your observation skills to problem-solve.
- Reduce the client's language demands by providing choices or responses. Don't ask open-ended questions, such as: "What do you want to drink? Instead, offer two specific choices: "Do you want tea or apple juice?"
- Ask questions that can be answered with a "yes" or "no." For example: "Do you want tea?"
- Help the client find the word he/she is searching for by encouraging him/her to talk about or describe the message; or write the words or draw a picture.
- Because word recognition lasts longer than word recall, you can use "twenty questions" to help the client find the right word. "Is it a person?" "Do you use it in the kitchen?"
- Offer the client the word. ("Is it your sweater that you want?")
- Don't rush the client or become impatient. Allow sufficient time for the client to find the word. Intervene when the client starts to show signs of frustration.
- If the client is unable to express himself/herself verbally, ask him/her to *show you*. Ask the client to take you the room or area, to demonstrate the task, or to write or draw the message.

- Listen for the intent or feeling of what the client is trying to communicate. Respond to the feeling message, even if it is different from the actual words.

  Example: A male client calling for his long-deceased mother may mean that he is lonely or scared. Acknowledge his feelings. Try to respond to his need for reassurance and caring by getting him to reminisce about his childhood or by sharing an activity with him. Note, however, that the client may be substituting the word "mother" for "wife." (An appropriate response would be: "Are you lonely for your wife, Mr. A.? She is out shopping and will be home soon.")

Note

It is not always possible to understand what the client is trying to say. Do not pretend to understand. There comes a time when you should stop trying to figure out the words. Acknowledge that you don't understand what the client is saying, and suggest that you leave the subject for the time being. You can come back to it later, if necessary. Divert the client to a pleasurable activity; for example, go for a walk or have a tea break. Later, perhaps, the message will become clear to you.

Perseveration

Some cognitively impaired clients may become fixated on and continuously repeat an action, sound, or word. This is known as "perseveration." The client will persistently carry out the same task or call out the same word, name, or sound until stopped by someone or something interfering with the activity. ***Sound perseveration*** in particular can be annoying to others. The following suggestions may prove helpful:

- Try to get the client's attention, provide reassurance verbally and with touch, and reorient the client to time, place, and person.
- Directly ask the client what he/she wants.
- Use the problem-solving approach to rule out a cause that is not attributed to the disease process.
- Try diversion. Some clients are comforted and quieted by holding a stuffed animal, or if given a snack.
- It is important that you do not become annoyed or shout at the client, or he/she will become more upset.
- If the client is able to understand, you may gently and firmly ask him/her to stop calling out — the calling out is annoying to you.
- It is important that you act in a calm, accepting, and reassuring manner.
- You may find it helpful to supplement your actions and words with the simple gesture of putting your hand over your mouth to reinforce the message, "be quiet."

The Severely Impaired: Suggestions For Communicating

Communication with the severely impaired individual is challenging. Although extremely difficult to continue to talk to people who respond minimally or inappropriately, it is important that the careworker do so, even during the late stages of the disease. Here are some suggestions for the careworker.

Continue to converse while doing care activities with the client. Talk about what you are doing, the weather, his/her/your family, special holidays or events, and so on.

Speak as if the client can understand everything you are saying. The client may not understand your words, but nonverbal communication can continue. The client may understand and be comforted by the "feeling" message you convey with your calm, pleasant, reassuring voice, your smiles, and your touch.

Even if you feel you are doing most of the talking, pause and give the client time to "process" your words. Do not talk nonstop!

"Quiet times" are okay, too.

Listen to the client's attempts to communicate. Although you may not be able to make sense of the words, you can relate to the tone of voice and underlying feelings. Does the client sound upset or content?

Use your keen sense of observation and your problem-solving skills to try to find out what the client wants.

Make the environment stimulating, but not monotonous. A dull, monotonous environment can be as bad as one that is too busy. The severely impaired often respond to pleasant touch and smell stimulation. They may enjoy petting soft, warm, furry pets or stuffed toys; or smelling brightly colored flowers.

Listening to music can be soothing. If it is played continuously, however, it is no longer noticed.

Be realistic. Don't expect too much of the client or of yourself. Even short periods of interaction are significant. Don't expect the severely impaired to communicate back to you. Be happy if they look at you or smile.

Don't give up! Don't stop communicating when the client appears unable to understand or to respond.

Summary

Communication is a vital part of life. Effective communication with the Alzheimer's client is the responsibility of the careworker. The cognitive losses experienced by the client impairs his/her ability to communicate effectively.

Throughout the client's life, it is important to keep communicating verbally and nonverbally.

Chapter 14
Stress Management

This chapter focuses on stress in the caregiving situation. It begins with a general discussion of stress and then looks at specific coping strategies to manage stressful situations arising in the care of the cognitively impaired client.

Stress management is a valuable life skill that is useful in the respite care situation.

Stress is a part of life. Stress is the body's reaction to events, both good and bad, that go on in daily life.

Types Of Stress

Some stresses are pleasant and make us feel good. Some stresses are negative and cause distress. The joy at winning a prize and the sadness caused by death are examples of positive and negative stresses. Some stress reactions protect us, giving us the energy we need to escape from danger. Other stresses motivate us and keep us going through challenging situations.

Sources Of Stress

Negative stresses can arise from several sources, including the environment (air pollution, noise, overcrowding, threats to our security, unfamiliar people and surroundings); catastrophic events (the loss of a relative, an accident, physical or mental or emotional illness); and life situations (travelling at rush hour, pressure at work, a family argument, a change in routine).

Signs Of A Negative Stress Reaction

Body signs include headaches; sweaty palms or body; shortness of breath; tightness in neck and shoulders; indigestion, stomachache; tiredness; inability to sleep as usual (difficulty falling asleep, early awakening).

Emotional reactions include sadness, fear, concern, exhaustion. Rather than facing the reality of a sad situation, some individuals attempt to cope by avoiding the real issue. They may offer "explanations" to account for the situation, or they may try other means to avoid facing the situation directly.

These reactions, known as defence mechanisms, may be difficult to recognize at first. Defence mechanisms are not willful lies. They are another type of emotional reaction to stress. Examples of defence mechanisms include:

- blaming others (projection);
- trying to explain why, avoiding the real issue (rationalization);

- feeling very unhappy (depression);
- fighting with others (aggression);
- shutting oneself off from others (withdrawal);
- acting like a child (regression);

Behavior reactions include irritability; becoming easily angered; crying easily; making frequent errors at work; or having accidents.

Individual Response To Stress

Everyone reacts to and handles stress differently. How we cope with stress is part of our behavior pattern. We can, however, learn new ways of coping with stress to minimize the negative effects.

Stresses In Respite Care

Caregiving can be highly stressful. The client, family, careworker, and coordinator all experience stress at times; at other times, they can be the cause of the stress.

One of the challenges facing the careworker is to cope with her personal stress as well as the stress arising from the family and the client.

It is important for the careworker to have an understanding of the stresses that are associated with the client, the family, and the carework situation.

Stress From The Client

The cognitively impaired client experiences confusion, memory problems, a loss of the ability to understand what is going on, and a loss of control over his/her thoughts, feelings, and actions. All of this, of course, and the ensuing behavioral and physical management problems, can be most stressful on the careworker as well as on the client.

Stress From The Family

The careworker must deal with the family members and their emotional reactions arising from the care situation. At times, the careworker may share some of the same feelings the family experiences. Those feelings are a source of stress.

Usually the careworker is not called in until a crisis occurs in the family. By that time, the family is experiencing feelings of frustration, fear, anxiety, and anger. Unfortunately, some families unintentionally direct their negative feelings toward the careworker. Doing so is hurtful to the careworker and becomes a source of stress. This problem is more pronounced when the family has unrealistic expectations of the careworker.

It is important for the careworker to know that negative feelings are common in these families. As hurtful as such incidents may be, it is important that the careworker try not to take them personally.

Usually, once the family members get the relief they need and see the competent care provided to their relative, their negative attitudes decrease.

For The Coordinator

To minimize stress involving the family:

1) Review carefully with the family/client the services provided by the careworker. Clarify the duties and responsibilities of the careworker, yourself, and the agency, as well as the limitations.

2) When briefing the careworker prior to client placement, be sure to review with her the duties and responsibilities as well as any special information provided by the family. Prepare the careworker for family/client problems.

3) Let the careworker know you are aware that some clients/families can be difficult to deal with and that the job is sometimes trying.

4) Provide regular opportunities for the careworker to discuss her job performance and the client. Carework can be isolating. Provide feedback, support, and recognition as well as opportunities for the careworker to enhance her carework skills.

5) Make regular home visits to see both the careworker and the family.

Handling Family-Careworker Problems

It is important that the careworker not confront the family caregiver directly. If the careworker is having a problem with a family member, it is recommended that she inform her supervisor, who will then discuss the issue and intervene as appropriate.

Avoiding Isolation

Everyone experiences stress from time to time. It is important in the caregiving situation that, as professionals, we leave behind our personal problems when with a client and concentrate on the job. This can be looked upon as a time to have a "break" from one's own problems. We may in fact start seeing our problems in a different perspective.

Careworker isolation can be avoided by allowing opportunities for participation in scheduled meetings or training sessions with the other careworkers in the agency, and through regular supervision. Discussion groups, continuing education programs, and staff meetings provide the opportunity for careworkers to share their experiences and feelings and gain mutual support.

The careworker should be encouraged to inform her supervisor, without fear of penalty, if she is feeling overly burdended or isolated. A change in client or scheduling, or time off, may be arranged. The careworker is not expected to endure unreasonable stress.

Stress can arise when the careworker becomes overly involved or too closely identifies with the client or family. It is sometimes difficult for a caring person not to become too involved. The professional careworker must find a balance that allows her to maintain her sensitivity while not taking on the emotional burdens of others.

Coping With Stressful Situations

Guidelines for the careworker appear in BASIC PRINCIPLES, Chapter 9. It is important to discuss ways of taking a safe "break" and emphasize that the careworker is not locked into a situation.

Summary

The caregiving situation can be stressful to the careworker as well as to the family. Suggestions have been made to assist the careworker in coping with stressful situations. The careworker has many options to relieve her stress, including a change of client.

Chapter 15
Coping With Dying And Death

Alzheimer's is a fatal disease. Its unpredictable course is characterized by a series of irreversible losses.

Coping with the stresses and feelings that arise in caring for a client who will not get better is never easy. The purpose of this chapter is to prepare the careworker for what she may experience as the client declines, and to provide her with coping strategies. We first review the client's perception of what is happening.

Client's Perception

During the final stage of the disease, the client does not appear to be aware of his/her surroundings or pending death.

The individual with Alzheimer's Disease will experience grief most dramatically at the beginning stages of the illness. In the early stages, many clients have the awareness that "something is wrong" with them. It is at that time that they experience their greatest stress. Some go through a type of mourning process over their losses.

Early Stages

Typically, Alzheimer's clients in the early stage will deny and try to cover up their memory loss and confusion. Often clients will keep lists, or make up stories and excuses to cover up their memory problems.

Not unexpectedly, clients who still have some awareness experience a profound sense of loss as their impairments and difficulties mount. The sense of loss may turn to fear. Depression often results when the grief becomes overwhelming.

Some clients take out their anger and frustration on those around them. Others try to blame those around them for intentionally making things difficult, which can be trying for both families and careworkers.

How clients experience the disease is highly individualized. Reactions depend in part on the client's previous personality, on the current life situation, and on the rate at which the disease is progressing.

Middle Stage

In the middle stage, insight is lost, and most clients are complacent and accepting. Some clients have behavior problems, which generally arise from their inability to communicate effectively and their difficulty to manage the usual activities of daily life.

Late Stage

During the late stage, clients appear to be unaware of their life situation or pending death.

Responding And Coping

The following are suggestions to help the careworker respond to and cope with the client's anxieties.

Early Stages

In the early stages of the illness, when the individual still has some awareness and insight into his/her condition, the challenge of coping with the client's anxiety and grieving process will be greatest for the careworker.

Some clients will not admit to or acknowledge their difficulties and may even resist people attempting to help them. The very presence of a careworker may be interpreted as a threat. The fact that she is there confirms the client's worst fears that "something is wrong."

Some clients want to talk about their losses. Allow them to talk. It is important that the careworker not offer advice or offer false hope ("everything will be well").

The careworker will have to be extremely tactful in her approach to the client, and be sensitive to client fears and losses.

It is important to be empathetic and supportive to the client.

The client or family may benefit from professional counselling. The careworker should inform the family and client (if appropriate) that there are family and client support programs available. The client's physician or the coordinator can assist the family in arranging counselling or support programs.

The careworker should inform her supervisor if the client is unduly anxious or upset, so that the appropriate support can be obtained.

Final Stage

Although during the final stage of the illness clients appear to be unaware of their condition, no one knows for certain how much awareness remains.

Assume client understanding on some level. Maintain communication, and do not say anything in front of the client that you do not want him/her to hear.

Careworker's Emotional Reaction

In caring for the client, it is normal for the careworker to experience a variety of feelings similar to those experienced by the family.

The careworker may go through a type of prolonged grieving process as she observes and comes to terms with the client's losses and his/her pending death.

The careworker must be prepared for this possibility. Although it is important that the careworker not become "hardened," it is also important that she does not get too involved with the client and family.

For The Coordinator

It is important for the careworker to be prepared for what to expect as the client declines.

It is normal for professionals to feel grief as they care for a client who is declining. The careworker is a feeling human being who has a personal relationship with the client. Like the family, some careworkers may need empathy and support.

To monitor the careworker's emotional reaction:

1) Watch for signs of the careworker becoming overwhelmed, either emotionally or physically, by the demands of care. Regularly discuss the case with the careworker. Find out how she is managing. Help her keep her perspective, particularly if you see signs of overinvolvement or overreaction.

2) If necessary, reassign the case.

3) In some cases, the careworker may require counselling. This option should be presented in a nonjudgmental, empathetic manner.

4) Provide opportunities for the careworkers to meet together and discuss their experiences and feelings about working with a dying client. It is helpful to have a resource person present who can offer suggestions.

Summary

One of the most difficult situations is caring for the client who is dying. Careworkers and other professionals are subject to feelings of loss and grief as the client, with whom they have a special bond, declines and ultimately dies. The careworker should be given support and empathy for this very human reaction.

Part IV

Daily Client Care

Chapter 16
Aspects Of Client Care

This chapter includes guidelines that apply to all aspects of caring for the individual with Alzheimer's Disease and related disorders.

Because of their importance, these guidelines are reproduced from BASIC PRINCIPLES. The coordinator is encouraged to emphasize these basic care principles during orientation and training and, from time to time, to review them.

Follow A Daily Routine

- Follow a daily routine that is familiar to the client. Consistent, predictable schedules are easiest for the client.

Simplify Activities

- Modify and adapt activities to the client's level. By simplifying activities, you will help prevent the client from feeling overwhelmed.
- Divide complex activities into simple one-step tasks. The ability to accomplish a task will give the client a sense of accomplishment and enhance his or her self-esteem.
- Present the tasks one at a time, in the order they are to be done. This is a way of getting around memory problems.

Use Repetition

- Repeat instructions or directions as often as necessary. Accept the fact that you will be required to repeat often because of the client's memory loss. Signs, lists, and other visual reminders are helpful to the client in the early and middle stages of the disease.

Encourage Involvement

- Encourage the client to do as much as he or she is capable of doing. Safely involve the client in the usual activities of life. Provide guidance and assistance along the way. Make sure the client does not become frustrated.

Provide Reassurance

- Provide the client with frequent reassurance. Reinforce your words of support and acceptance with a warm smile, a reassuring touch, and a gentle voice.

Be Respectful

- Always treat the client in an adult manner, with dignity and respect. Do not talk about the client when he or she is present, unless the individual is included in the conversation. Continue to talk to the individual even when the condition is severe.
- Act in a calm and relaxed manner at all times. Show sensitivity, acceptance, patience, and understanding to the client. Do not rush or scold the client. Leave enough time to accomplish tasks so you do not have to rush. Never show annoyance, irritation, or anger toward the client.

Practise Safety

- Make sure the client's surroundings are safe and manageable. Surroundings should be kept neat, well-lighted, familiar, and comfortable. Keep walkways open and clear (to avoid tripping), and avoid unnecessary background noises. Because these safety features are important at all times, you may want to discuss them with the family.

Be Observant

- Use your skill of observation to learn what the client is capable of doing, to recognize signs of change, and to ensure continued safety and well-being. Modify your expectations and actions to meet changing client needs and capabilities.

Follow Up

- Share your observations and problem-solving techniques with the family.
- Report to your supervisor changes in the client's condition or in a family situation.

Client Care Guidelines

These guidelines apply to all aspects of caring for the individual with Alzheimer's Disease. Following them should help make life easier for both the client and those providing care.

Chapter 17
Behavior

Behavior is the term used to describe how a person acts. Caring for the individual with Alzheimer's Disease can be challenging because of the behavior problems caused by cognitive impairment.

In this chapter, we look at some of the factors that influence behavior, examine the effect of Alzheimer's Disease on behavior, and suggest ways for the careworker to promote enhanced client behavior.

Factors Influencing Behavior

Behavior is influenced by many factors, both within and around the individual, that relate to the past as well as the present. Many theories have been developed to explain the complexities of behavior.

Factors within the individual that may affect behavior include:

- physical, emotional, and mental health;
- thoughts and feelings; and
- education and life experience;

Factors external to the client include:

- family, friends, and community; and
- cultural and ethnic background.

Behavior is a form of expression and one of the ways we communicate. There is always a reason behind a behavior, but, because of so many complex factors, that reason is often difficult to determine.

Behavior And Alzheimer's Disease

The client with Alzheimer's Disease has little control over his/her behavior. Cognitive impairment and mood changes experienced with the disease influence behavior in unpredictable and sometimes disturbing ways.

Although there can be physical, social, or other identifiable reasons for behavior problems, there are unpredictable events that cannot be fully anticipated by the caregiver — professional or family.

Behavior problems are more likely to occur when the client:

- feels overwhelmed, angry, or frustrated;
- does not understand what is going on;
- is unable to communicate effectively;
- has difficulty coping with usual life activities;
- senses that others are upset with him/her; or
- feels threatened.

Behaviors arising from those situations are considered to communicate a message; they have a meaning. Sometimes, however, there is no meaning attached to the behavior; the behavior is simply due to the effect of the disease on the brain.

Different Patterns

Just as every client is different, so the behavior shown is unique to the individual. As well, behavior patterns fluctuate within an individual over the course of the disease. Not every Alzheimer's client will display behavior problems.

Some behaviors create serious problems, some are harmless, and some are merely annoying to others.

Effect Of Cognitive Impairment On Behavior

Cognitive impairment has a major influence on the behavior of the individual with Alzheimer's Disease. This negative effect is compounded in the early stages by the person's own emotional response to cognitive losses. Clients are confused and disoriented, having forgotten their identity, where they are, the people around them, and how to behave. Not understanding what is going on and unable to communicate effectively, clients are often overwhelmed by feelings of fear, anxiety, grief, anger, or depression. It is not surprising that the behavior of the cognitively impaired individual will be affected.

Because of the memory loss experienced by all Alzheimer's clients, most episodes of difficult behavior do not last long. The client can usually be easily distracted and will soon forget what was upsetting him/her.

As the disease progresses, behavior patterns usually change. Clients become less aware as the dementia increases; their anxiety and fear diminish, they become calmer, and problem behaviors usually decrease.

Effect Of Feelings On Behavior

As noted, feelings influence behavior. Feelings are often well-preserved even when the dementia is severe. Feelings of anger, frustration, sadness, and fear can trigger problem behaviors. In the early and middle stages, clients are able to talk about their feelings. The careworker should ask the client how he/she is feeling and should learn to respond to the client's feelings. Nonverbal expressions are often more revealing of client feelings than are verbal statements, which may be impaired or screened.

Responding To Client's Feelings: Guidelines For The Careworker

By recognizing and responding to the client's feelings, whether expressed verbally or nonverbally, the careworker may be able to prevent episodes of difficult behavior. Some helpful approaches are described below. Any approach has to be tailored to the client's needs at the time.

Direct Communication

If the client is feeling sad, lonely, or depressed ("I don't want to live any more"), the careworker should reply with an empathetic statement. For example: "I understand that you are finding things have become very difficult. You must be feeling very bad about it. Can you tell me more about what you are feeling?"

Caution

The careworker should be cautioned to be alert for signs of extreme distress and sadness in the client. If the client is talking about wishing his/her own death or is trying to harm himself/herself, the careworker should notify the family and the supervisor at once so that protection and additional assistance can be obtained.

If the client becomes more agitated from the talk about feelings, the subject should be changed. The careworker should distract the client by diverting his/her attention. Clients early in the disease may benefit from specialized counselling that is available. (The coordinator should be aware of the counselling services available through psychogeriatric units and community services.)

Using Indirect Communication

If it is too stressful or beyond the client's ability to talk about his/her feelings, the careworker can respond to the feelings without talking about them directly. For example, the careworker who sees that a client looks sad or anxious should be encouraged to take the time to sit down and talk to the client. Careworker time, attention, and interest will enhance client self-esteem and self-worth, will have a calming and reassuring effect, and will help the sad feelings to pass.

Effect Of Surroundings On Behavior

The behavior of Alzheimer's clients is influenced by what is going on around them. Excess activity or noise may confuse and overwhelm clients and trigger problem behaviors. The careworker should check to ensure that:

- lighting is adequate (to avoid shadows);
- room temperature is comfortable (not too dry or too damp);
- air is fresh (no unpleasant or strong odors);
- room is neat and tidy (free of clutter);
- furniture is arranged to allow ease of client movement (clear and open pathways) and kept in same place for familiarity;
- rugs are securely fastened to the floor;

- floors are not slippery;
- room is quiet (turn off radios, TVs, or record players that are not being used by client); and
- likelihood of sudden interruptions is minimized (be careful of other people rushing through the room).

The Meaning Behind Behavior Outbursts

One of the ways the Alzheimer's client communicates is through behavior. As noted earlier, there is a meaning behind most behaviors. Behavior is influenced by many factors, including the disease process itself.

Behavior outbursts may indicate the client is overwhelmed. Perceiving the anger and impatience of careproviders, the client becomes confused, angry, frustrated, upset, or afraid.

Unfamiliar people, places, and activities can be frightening to the client and trigger problem behaviors.

Because the client loses the ability to communicate effectively, distress or discomfort related to a variety of causes (including feeling unwell, hungry, tired, in pain, or constipated, or suffering from a toothache) will be expressed through a change in behavior.

There are times when the dementia produces a behavior pattern that has no apparent meaning: it arises as part of the disease process.

Sudden Change In Behavior

A sudden change in behavior signals that a change has occurred in or around the client. It is important to look for the underlying cause. The problem-solving approach may be used to determine (or rule out) the cause so that appropriate measures can be taken.

It is essential that the careworker be prepared for sudden changes in the client's behavior and know how to manage them effectively. The careworker will have to be flexible in the approach taken. Because the client is always changing, some techniques will work on one occasion but not on another.

The careworker can often influence the client's behavior. By following the client care guidelines, most preventable causes of difficult behavior can be avoided or limited. Unfortunately, little can be done to prevent the kinds of difficult behaviors that arise because of the brain changes which occur with the disease.

Behavior Patterns: Two Categories

Some client behaviors may be annoying, some embarrassing, and some dangerous to the client or others. Behaviors that are harmless and leave the client calm and content can be allowed to continue. Behaviors that are dangerous or are causing the client to become upset and agitated must be stopped.

A very simple way to look at behavior types is to classify them into two general categories. There are those behaviors that are desirable to maintain and promote, and there are those disturbing or problem behaviors that are best avoided or limited.

Desirable Behaviors

Examples of behaviors to be encouraged and supported in the client are self-care activities (feeding, dressing, bathing, grooming, toileting); social skills and communication; and participation in household tasks and recreational activities to the extent able.

Undesirable Behaviors

Examples of serious undesirable behaviors in the client that must be stopped include: wandering, aggressiveness, hitting, shouting, hallucinating, suspiciousness, and sexual inappropriateness.

Some behaviors are undesirable because they are annoying to others, but they are not necessarily dangerous to the client. Examples include perseverated (persistently repeated) actions (such as drying the same dish for half an hour), or the persistent calling out of a sound or name.

Reinforcing Desirable Behavior

There are many strategies used to reinforce and promote desirable behavior. Reinforcing appropriate behavior is one of the best ways to prevent undesirable behaviors.

Tips For The Careworker

Follow a routine schedule with the client. A predictable routine is comforting to someone who is confused and suffers from memory problems. It is also the easiest to manage. Controlling the routine decreases the likelihood of problem behaviors occurring.

Allow the client to function at his/her best level. Encourage the client to do as much as possible independently, even if it takes much longer to complete a task. Taking over and doing too much for the client is as bad as not doing enough. If the client does not continue to use remaining skills, they will be lost even sooner.

Get to know the client. It is important to know what the client is capable of and how the client reacts in specific situations. This information can be acquired through careful observation and by talking to the family. Getting to know the client includes gaining an understanding of the "feeling" messages that he/she expresses.

Reinforce good behavior. Acknowledge, praise, or reward good behavior in an appropriate manner. It is important that you are sincere and that the recognition is appropriate for the activity. A smile and thank you are appropriate to show appreciation for a client's help with routine tasks. Particularly in the early and middle stages of the illness, when aware of his/her losses, the client can tell the difference between routine activities and significant accomplishments. It is humiliating to be overpraised for simple tasks. It is also humiliating to be treated like a child. Even with limited awareness, the client is hurt when treated in such a way.

Chapter 18
Difficult Behavior

Managing difficult behavior is one of the greatest challenges facing the careworker. In this chapter, the difficult or problem behaviors that sometimes occur with Alzheimer's Disease and related disorders will be reviewed in a general way. Specific strategies appear in BASIC PRINCIPLES. The careworker should review especially Chapter 6 (A Problem-Solving Approach to Care), Chapter 8 (Communication), and Chapter 12 (Difficult Behaviors).

What Is Difficult Behavior?

Difficult or problem behaviors are those behaviors that:

- are harmful or potentially harmful to the client's health, safety, or well-being;
- occur when the client is upset, anxious, or distressed;
- are harmful or potentially harmful to others or to material property.

What Does Problem Behavior Communicate?

Most behaviors communicate a message. However, because of the many factors that influence the client's behavior, that message may be difficult to understand.

The underlying message may reflect the client's physical condition, such as hunger, fatigue, feeling unwell, or the need to go to the bathroom. Some behaviors reflect the client's feelings of anxiety, loneliness, fear, stress, or boredom. Some behaviors express the client's feelings about the surroundings and about the people providing care. Some behaviors are considered to reflect the client's efforts in trying to cope with and regain control over his or her life. Wandering, for example, is thought by some to reflect the client's search for a former home and life. Finally, some behaviors are considered to be related solely to the illness: the brain no longer functions properly. Although we have difficulty attributing a meaning to disease-originated behaviors, that does not mean the behavior has no meaning to the client.

Often, checking out the client's physical needs, controlling environmental factors, and following the client care guidelines help to prevent or limit many problem situations.

Analysing A Difficult Behavior

The careworker should always keep in mind the goal of client safety and well-being. She should stop and think about the behavior, and should consider the following in making a decision on the appropriate action:

- Is client safety or well-being compromised?
- Is the behavior dangerous or harmful to the client, to others, or to property?
- Is the behavior "bothersome" only to the careprovider? If that is the case, she may be better off selectively tuning it out and focusing on something else, while continuing to monitor and supervise the client.

Repetitious Behaviors

One characteristic of the behavior in dementia is that it is often repetitious. The individual may get fixed or stuck on a specific activity and continue it until stopped by someone or something. This behavior is known as perseveration. It is usually harmless to the client, although it can be annoying to others. The repetitive behavior may be a gesture or a motion, or it may be a sound or word called out. Two common examples of perseveration are sweeping the same section of the floor over and over, and wiping one dish again and again long after it is dry.

Perhaps most annoying is verbal perseveration, where the client calls out a sound or name over and over, for no apparent reason. This behavior usually happens in later stages of the disease.

General Principles In Behavior Management

Managing behavior requires an understanding of the client's:

- physical, cognitive, and emotional condition;
- needs;
- surroundings;
- perception of what is happening around him/her; and
- perception of the attitude and feelings of those providing care.

Preventive Strategies

It is preferable to avoid or prevent situations that may lead to difficult behaviors. The careworker should learn to recognize warning signs and act appropriately. (Preventive tips appear throughout Chapter 12 of BASIC PRINCIPLES.)

Managing Difficult Behaviors

Managing difficult behaviors makes use of the careworker's knowledge, skills, experience, and ingenuity. As always, client safety is the first concern.

This section reviews the problem-solving approach to managing difficult behavior and presents guidelines for the careworker.

The Problem-Solving Approach

The problem-solving approach, which works well in managing difficult behaviors, has sufficient flexibility to allow the careworker to try several options. Managing a difficult behavior requires an immediate action and a remedial action.

The immediate action — stop the behavior:

- Remove the client from danger.
- Divert or distract the client.

These actions must be done in a manner that will ensure client health, safety, and well-being, and not cause additional upset. It may be necessary to lead the client to a safe place.

The remedial action — determine the underlying cause:

Use the problem-solving approach to determine the underlying cause of the behavior, then take the appropriate corrective actions to prevent or avoid its recurrence. Often several actions are necessary to calm the client and resolve the problem situation.

Reminders For The Careworker

Whenever possible, involve the client in the problem-solving process. In early and middle stages, the client will be able to tell or show you what is troubling him/her.

Most episodes of difficult behavior do not last long and are soon forgotten by the client. Remember:

1) Remain calm and do not show annoyance or anger toward the client.
2) Difficult behaviors are part of the disease process; the client has no control over them.
3) Patience, understanding, and acceptance of the situation will help you cope with unpredictable and sometimes trying situations.
4) Every client is different. Every response has to be tailored to the individual.
5) There is no "one right way" to overcome difficult behaviors. Often, trial and error are necessary before finding the right response.
6) It is important not to forget the person behind the disease.
7) Don't give up!

Chapter 19
Personal Care

Personal care activities, which are related to the individual's physical needs of life, include eating, bathing, grooming, dressing, and toileting. Safety, exercise, and sleep are also components of personal care.

The client with Alzheimer's Disease requires increasing amounts of assistance to meet these important physical needs of life as the disease progresses.

This chapter reviews some of the special considerations that the careworker should be aware of when assisting the Alzheimer's client with personal care activities.

Meeting Personal Needs

There are several types of needs, the primary ones being physical, emotional, and social. Needs often overlap. In meeting one need, the individual's other needs must also be taken into consideration.

For example, when feeding a client, one must be aware of the need for self-esteem and the client's desire to have some control over life. Most clients far prefer to feed themselves than to be fed by someone else. One must also consider the importance of following any religious rituals (for example, praying before eating); respecting ethnic food preferences; and offering foods that the client is familiar with and enjoys. These additional considerations are nearly as important as the nutrients.

Performing their own personal care activities means that clients are involved in purposeful tasks and gain a sense of satisfaction and accomplishment.

Personal Care Activities

The personal care activities that the careworker will likely assist the client with include:

- personal hygiene (for example, bathing, showering, tooth-brushing);
- feeding;
- toileting;
- dressing;
- grooming (hair-combing, putting on make-up); and
- supervising medication administration.

Guidelines For The Careworker

The Client Care Guidelines presented in this Resource Guide and in BASIC PRINCIPLES should be followed by the careworker when assisting the client with personal care activities. Specific techniques are listed in Chapter 13 of BASIC PRINCIPLES, Personal Care Activities.

Summary

Personal care activities are private activities, and providing assistance requires tact and diplomacy. A calm and professional manner will help the careworker assist the client with these essential life activities.

Chapter 20
Nutrition

A well-balanced diet and adequate fluid intake are important for good general health at any age.

Food provides the energy and nutrients for the body to function, grow, and maintain and repair itself. The type and amount of food consumed can influence how the body functions and how the individual feels.

Water is an important part of a healthful diet, second only to oxygen as a necessity of life.

This chapter reviews some of the nutrition-related problems that a cognitively impaired individual may experience.

Food Selection

Canada's Food Guide is a valuable reference in planning nutritional meals for anyone.

The client's dietary preferences, food customs and rituals, and special medical needs should be part of the initial assessment. This information should be passed on to the careworker.

Food is not only a necessity of life; it is also a source of pleasure for many people. In many societies, eating is a social and recreational activity. Mealtime is often the highlight of the day for the elderly.

We all develop our own food and eating habits over a lifetime. These familiar practices are often hard to change. It is important to try to accommodate personal preferences in meal planning. There is much choice within food categories and with most specialty diets, and so the food selected can be both satisfying to the individual and medically appropriate. Some "preferred" foods may not be allowed on a diet, and should be avoided, but an effort should be made to find other, permitted foods that the individual likes.

In the presence of other illnesses, or as the condition worsens, consultation with a nutritionist may be required.

Special Dietary Considerations

The Aging Process

Normal Biological Age Changes

Many normal age changes affect the nutritional requirements and food intake of the elderly individual.

Body processes slow down. The body takes longer to digest food, and does not digest food as well. Problems with teeth may prevent proper chewing and cause the individual to avoid foods that are hard to chew. Some elderly individuals suffer from constipation.

Because the elderly tend to be less physically active than others, they may require less food than in the past.

Chronic Illness And Disability

Some chronic illnesses common in the elderly require special diets as part of their treatment. Conditions requiring special diets include, among others, diabetes, some heart diseases, and kidney disease. Calorie-reduced, low-salt, low-cholesterol, and high-fibre diets are examples of commonly used diets. Such diets are called therapeutic diets; they are prescribed by the physician. Often a nutritionist is consulted for specific dietary instructions.

Other chronic illnesses, such as arthritis, can affect the food intake. The painful joints, weakness, and limited motion make it difficult for individuals to buy, prepare, and eat some foods.

Hand tremors, such as in Parkinson's Disease, make it difficult to prepare food or feed oneself.

The senses of smell and taste are diminished in the elderly. Food may taste bland and lose its appeal. There is often a tendency for the elderly to use too much salt or sugar in an attempt to improve the flavor of food. The use of excess salt or sugar can be harmful and should be avoided.

Psychological Factors

In some elderly individuals, emotional reactions can lead to unhealthy and dangerous overeating or undereating. Emotional upset, sadness, depression, and loneliness often affect the appetite.

Food has a social component, and many social activities and religious festivals involve food rituals. Food is often a source of pleasure. Food treats are commonly used as a reward.

Social And Financial Factors

Limited income may prevent some elderly individuals from buying nutritious foods. Some frail or disabled individuals may not be able to get to the store without assistance or transportation. Those living alone may "not bother" to prepare and eat meals alone. Some clients may be eligible for financial assistance.

Cognitive Impairment

Memory loss and confusion can contribute to nutritional problems. Cognitive impairment may cause clients to:

- forget how to shop, prepare food, eat, use eating utensils, chew, or swallow;
- forget if they ate earlier, or when they last ate;
- not recognize what can be eaten. Clients may lose the ability to distinguish a food item from a nonfood item, or be able to detect if food has gone bad, is cooked properly, or is too hot or cold.

Alzheimer's Disease And Food Intake

All the issues discussed above may apply to the client with Alzheimer's Disease.

One additional caution should be given about the food intake of clients with Alzheimer's Disease. Many clients with Alzheimer's Disease have a large appetite and consume huge amounts of food without gaining weight. This tendency is particularly common in the middle stage of the disease. At that time, the client is physically well and often very active. Many clients walk a lot and expend a good deal of energy, making them hungry. It is important to ensure that clients receive enough food to maintain their activity level and weight.

In the last stage of the disease, when the client is bedridden, food requirements decrease.

Feeding The Client: Tips For The Careworker

With feeding, as with other activities, the Client Care Guidelines (see Chapter 16 of this manual) should be followed. The following guidelines are related specifically to feeding and food preparation.

1) Prepare nutritious meals. Make choices according to Canada's Food Guide or the client's prescribed therapeutic diet.
2) Keep meal presentation simple. Especially at later stages, avoid having an assortment of utensils, dishes, or ornaments on the table that may confuse the client.
3) Check the temperature of the food before serving.
4) Use nonskid plates and easy-to-handle cutlery. Special cutlery is available that is lightweight and has thick, easy-to-grasp handles designed for clients who have limited motion in their hands. (A consultation with an occupational therapist may be arranged if the client needs such assistive devices.)
5) Make mealtime a relaxed, pleasant experience. Do not rush the client or show annoyance or impatience.
6) Before and after eating, remind the client to go to the bathroom and to wash his/her hands (assist as necessary).
7) A protective apron or adult bib is useful to protect the client's clothing.

8) When the client's impairment increases:
   - Give frequent, step-by-step reminders.
   - Demonstrate the required activity.
   - Guide the client through the motion (place your hand over the client's) until the client is able to take over.
9) In the later stages, when the client has difficulty with self-feeding, use alternate food presentations:
   - a one-dish meal (casseroles) that can be eaten with a spoon;
   - "finger foods" — sandwiches, pieces of cooked chicken or other meat, vegetables, fruit, or cheese -- that can be picked up and eaten by hand when utensils can no longer be managed;
   - thick liquids or semi-solid foods that the client can drink out of a cup (when the client can no longer chew, or when fine hand control is lost).
10) In late stages, the client will have to be fed. A nutrition consultant may be required.

Feeding The Client — General Reminders

It is important to be pleasant, calm, and relaxed when feeding a client. Allow plenty of time. Do not rush the client. It is helpful to:

- sit beside the client;
- place small amounts of food on the spoon;
- show the client the spoonful of food before giving it to him/her;
- tell the client, in a calm voice, what the food is and what you are doing;
- remind the client to open his/her mouth;
- touch the spoon gently to the mouth;
- remind the client to chew and swallow;
- offer the client a drink of water (or juice or milk) regularly;
- observe the client carefully — watch the timing of spoonfuls, and make sure the client is swallowing;
- watch for signs of choking or client discomfort;
- repeat short, friendly reminders, one step at a time.

After Eating

After the meal, assist the client in going to the bathroom and in carrying out personal hygiene.

The client will likely be tired and want to rest after eating. If the client does not nap, plan quiet activities, such as listening to music, for at least an hour after eating.

Record The Food Intake

Because it is important to ensure the client receives an adequate diet, it is recommended that the careworker keep a record of what and how much is eaten, and the time of the food intake. A sample dietary record is shown.

Dietary Record

Client's Name _____

Date, week beginning _____

Day	Breakfast	Snack	Lunch	Snack	Dinner	Snack
Monday						
Tuesday						
Wednesday						
Thursday						
Friday						
Saturday						
Sunday						

(Estimate portion size or amounts; for example, half an apple, one cup of milk. Do not forget to record liquids.)

Special comments:

_____

_____

_____

Careworker's Name _____

Special Feeding Problems

Cognitive impairment causes problems with eating that sometimes present a special challenge to the careworker. The following chart lists some common disorders and provides suggestions for the careworker.

Problem	Suggestion
Constant eater	• Break three main meals into ten small "snacks" that can be eaten through the day. • Keep pieces of fresh vegetables or cheese handy for snacking. • Post a written schedule of meal times, and refer the client to it.
Client keeps asking when the next meal is	• Post a written schedule of meal times, maintain the routine, and refer the client to the schedule. Post the schedule near a clock that the client can see. • Try to distract the client by introducing a new activity.
Client refuses to eat	• Serve favorite foods. • Do not rush the client or act impatient. • Refusal to eat may be a sign of an underlying illness or injury and should be investigated. Look for signs of dental problems or other sources of discomfort (client may need to go to the bathroom). • Offer soft foods or liquid supplements. • The client may have forgotten what to do. Demonstrate the activity one step at a time. • Do not argue or threaten. An impatient or angry response by the caregiver will be sensed by the client, causing additional stress, confusion, and feelings of rejection. • If gentle persuasion still fails, take the food away and wait ten or fifteen minutes before reintroducing it. By then the client may have forgotten earlier objections.

Problem	Suggestion
Choking	• Observe the client to ensure he/she is able to chew and swallow food safely. Offer small portions at a time. Serve food that is of a smooth texture and consistency. Separate liquids from solids. The last spoonful should be smooth and easy to swallow (for example, a gelatin dessert). Make sure the client is sitting upright, with the head tilted slightly forward.

Difficulty Chewing

When cognitive impairment or tooth loss makes chewing difficult, it will be necessary to specially select and prepare foods from each of the essential groups.

Category	Selection/Modification
Milk and milk products	Milk, cottage cheese, yogurt, milk puddings, cream soups.
Meat, fish, and poultry	Ground, chopped, thinly sliced, pureed, food processed, stewed, roasted, boiled. Alternates include eggs, peanut butter, baked beans, lentil soup.
Breads and cereals	Cooked whole-grain cereals, soft breads, cereals moistened generously with milk or water.
Fruits and vegetables	Canned, cooked, stewed; grated, finely chopped, mashed; soft fresh fruits (bananas, very ripe peaches); juices.

Constipation

Constipation is a frequent problem experienced by the elderly, because of normal age changes (the slowing of the gut) and decreased activity. Inadequate fluid intake and insufficient amounts of fruit and vegetables also contribute to this problem. Constipation is a side-effect of some commonly prescribed medications. Sometimes constipation is an effect of another illness and requires medical attention.

Here are some simple dietary measures than can be helpful in preventing constipation when there is no other underlying medical cause.

Give the client at least six to eight glasses of liquids a day. Choose water, milk, unsweetened fruit or vegetable juice, or decaffeinated coffee or tea.

Increase dietary fibre gradually. Natural fibre is found in many foods, including fruits and vegetables, beans and legumes, and bran cereals. (A nutritionist or a public health or medical consultant should be contacted.)

Moderately, and with the authorization/supervision of the client's physician or physiotherapist, the client's level of physical activity may be increased. Light exercise, such as walking, is a nondietary modification that is sometimes helpful in managing constipation. Walking is one activity that many cognitively impaired clients continue to enjoy and perform easily.

Medical Referral

All new incidents of constipation require medical attention. Similarly, a worsening of the condition or other complications occurring along with the constipation must be assessed by the client's physician. The family or the supervisor should be alerted so that the appropriate medical follow-up is obtained.

Any significant modifications to the client's nutritional intake or exercise routine should be authorized by, and made under the supervision of, the physician or other team member so authorized.

Food Safety And Food-Handling Techniques

It is important to handle foods properly to avoid the incidence of contaminated food.

Food-Handling Tips

1) Store foods properly. Perishables should be well wrapped and stored in the refrigerator.

2) Wash hands thoroughly before handling, preparing, serving, and eating food. Make sure all utensils and surfaces are clean. Use hot, soapy water to wash. Rewash hands and utensils after handling raw meats, fish, poultry, and eggs.

3) Wash fruits and vegetables before eating.

4) Use utensils, rather than hands, to mix or handle food.

5) Cook foods as recommended, and serve them hot. Leftovers should be covered and refrigerated immediately to prevent spoiling.

6) Be aware of foods that have gone bad. Check "best before" dates; throw away food with a bad odor, an off taste, or a color change; do not use cans that are swollen or rusty.

Snack Foods

Food is frequently used as a diversion and as a reward. Snack foods should be low calorie and low cost. They should taste good and contribute to the client's overall nutritional intake. Avoid excessively sweet, salty, greasy, or fried foods. Some good snacks appropriate for the cognitively impaired client are:

- raw vegetable sticks,
- cheese and crackers,
- small sandwiches,
- unsweetened juice,
- milk, and
- fruit.

Summary

Ensuring the cognitively impaired client receives a balanced diet is one of the careworker's responsibilities. When in doubt, the careworker should check with the family or with her supervisor. Consultation with a nutritionist may be required.

Chapter 21
Medication Therapy

Drug therapy has had a major impact on the treatment and management of illness and disease in the last three decades.

Drugs, also known as medications or pharmaceuticals, are potent chemical agents. Prescribed medication therapy is tailored by the physician to the individual's personal needs. The same agent that can provide a cure or relief to some people will have harmful or even fatal effects on others. Just as no two people are alike, there are individual differences in the way people react to drugs.

The effect a drug will have on an individual is influenced by many factors, including: age, sex, race, health status (present and past), the presence of other illnesses, other medications taken, and special diets. Some individuals are more sensitive to the effects of drugs than are others, and some may experience allergic reactions. For these reasons it is important to take only those medications prescribed for you by your physician.

Over-The-Counter (Non-Prescription) Drugs

The same caution must be used with home-remedies bought "over-the-counter." The use of over-the-counter products on a long-term basis should be under the supervision of the physician or pharmacist. Dosages printed on the package are given as guidelines and should not be exceeded unless on the physician's instructions. Note any particular cautions written on the label. If in doubt, have the family check with the physician or the pharmacist.

Drug Use In The Elderly

As we age, there is an increase in the incidence of chronic illness. This often results in increased use of medication by the elderly. While medications used properly can have a beneficial effect, they also carry a risk potential. The more medications an individual is taking, the higher the risk of developing adverse effects.

It is vitally important that all medications, whether prescribed or obtained over-the-counter, are supervised by the physician looking after the individual's health.

Sensitivity To Drugs: The Young And The Elderly

Infants and the elderly, because they are not able to process drugs effectively, are more sensitive than others to the possible undesirable side-effects or adverse effects of drugs. Drugs are chemically altered in the body, in processes known as metabolism and elimination. The liver and kidney are the main body organ systems involved in these processes. In infants, the liver and kidneys are not completely developed and are unable to handle these processes efficiently. Similarly, liver and kidney function deteriorate with age, impairing drug-processing in the elderly.

Drug Sensitivity In Clients With Alzheimer's Disease

Drugs have a different effect on an individual suffering from Alzheimer's Disease than on other individuals of the same age. This is particularly evident with drugs that act on the brain. Prescription drugs that act on the brain include tranquillizers, sleeping pills, antidepressants, and drugs for Parkinson's Disease. Over-the-counter drugs that act on the brain include sleeping preparations, cough and cold remedies, allergy medications (antihistamines), and motion-sickness medications.

Multiple Drug Use And Side-Effects

The more drugs taken at the same time by an individual, the greater the likelihood that drug interactions will occur. The effect of a drug interaction varies. In many cases, the desired effects of the drugs are lost. Some drugs may cancel one another out. In other cases, the effect may be greater: a side-effect or "adverse reaction" may occur, or, in the most extreme instances, a toxic or fatal reaction may result. The prescribing physician will monitor the effect of the medication on the client and tailor the dosage to minimize the occurrence of side-effects.

Side-Effects Resembling The Symptoms Of Alzheimer's Disease

Some common side-effects of drugs resemble symptoms associated with Alzheimer's Disease. It is important to observe clients carefully for signs of change (symptoms) in their condition and to report those findings to the supervisor and family to ensure the appropriate medical follow-up.

Some common side-effects that resemble the symptoms associated with Alzheimer's Disease and related disorders are listed below. These symptoms may also occur in the presence of many other illnesses and disease states that may be treatable. If these symptoms occur, particularly if they represent a change in the client, a medical consultation must be obtained to reassess the client.

Drug side-effects similar to the symptoms of Alzheimer's Disease include:

- confusion,
- forgetfulness,
- memory loss,
- disorientation,
- comprehension problems,

- drowsiness
- slurred speech, and
- slowed reaction time.

Other common side-effects of drugs include:

- dry mouth,
- tremor,
- constipation,
- diarrhea,
- urinary retention (unable to pass urine),
- muscle stiffness, rigidity,
- rash,
- hives,
- headache, and
- gastric distress.

Many side-effects can be reduced or eliminated by modifications in the medication therapy, and the prescriber should be informed if any of the above or other reactions occur. Never change a medication regimen without consulting the prescriber or the pharmacist.

Symptoms Of Illness In The Elderly

In the young, the symptoms of illness are well-defined and specific, and include high fever and localized pain. In the elderly, however, the symptoms of illness are general and nonspecific. Two elderly people may appear to have the same symptoms, but that hardly means they both have the same condition or require the same medication. The physician has the special training to diagnose and treat medical conditions.

Compliance

In prescribing medication, the physician considers many factors in determining the dose that will result in maximum desired effect with minimal side-effect.

Drug compliance means taking medication exactly as prescribed (the right drug, in the right dose, at the right time). The importance of such compliance is clear.

Noncompliance, or not taking the drug as prescribed, is considered to be drug " misuse" or "abuse." Noncompliance means:

- not taking the drug at all,
- taking the wrong dose, whether too much or too little, or
- taking the drug at the wrong time(s).

Noncompliance may be intentional or accidental. Noncompliance is common in the elderly. Forgetfulness, confusion, difficulty seeing, and some physical disabilities may result in the client not taking the medication as prescribed.

Coordinator's Role

At the time of the client assessment for service, find out from the family (or the client) about the medications the client is taking and any side-effects or cautions the careworker should be aware of. Be sure to pass this information on to the careworker.

It may be helpful for you to remind the family to have all the client's medications, prescribed and purchased over-the-counter, reviewed by the client's primary physician on a regular basis. Regular re-evaluation of medication therapy by the prescriber is important, particularly if the client is experiencing side-effects or a change from the usual (behavior, mood, physical function, ability).

With the family's authorization, the coordinator may discuss the client with the physician or other designated team member when there is a severe behavior-management or other care problem.

Pharmacists are readily available to discuss drug side-effects and other considerations related to the following of a medication regimen.

For specific careworker guidelines related to medication therapy, refer to BASIC PRINCIPLES, Chapter 13 (Personal Care Activities).

Social Drugs

Alcohol, nicotine, and caffeine are all drugs that are commonly used in our society. Despite their common use, they are potent chemicals that affect the brain and, therefore, especially affect people with Alzheimer's Disease. The effects of each of these three drugs on the cognitively impaired client will be reviewed briefly.

Alcohol

Alcohol is a drug that acts on the brain. Alcohol is also a neurotoxin, which means it can destroy brain cells. Because of the brain damage associated with Alzheimer's Disease, the client is more sensitive to the effect of alcohol. This change in tolerance to alcohol means that small amounts can cause much greater impairment than normally would be expected.

Alcohol impairment causes symptoms that are similar to those seen in Alzheimer's Disease. Alcohol may make the individual seem more impaired. Alcohol side-effects include:

- increased confusion,
- recent-memory problems,
- loss of inhibition,
- increased restlessness and sleep disturbances, and
- increased urine output (which can be a problem in incontinence).

While the effect of alcohol, like other drugs, is individualized, it is recommended that alcohol be used with moderation, if at all. Clients should be observed carefully and their condition monitored to assess the effect of alcohol. If the individual experiences increased confusion or other adverse effects, alcohol use should be restricted or stopped.

At a party or in other social situations associated with drinking, a nonalcoholic beverage may be substituted. The alcohol can be left out of mixed cocktails, and alcohol-free beer and wine can be provided.

Smoking

Nicotine is a drug. Besides the known health risk of lung cancer, there is another major safety risk with smoking: fires or burns. This risk presents an even greater problem when the smoker is cognitively impaired.

If smoking is a "necessity" for the client, it is recommended that the careworker remain with the client when smoking. Matches or lighters should not be left with the client. Matches and lighters should be safely locked away and kept under the supervision of the careprovider.

Caffeine

Tea, coffee, and chocolate all contain caffeine. Caffeine is a drug. Caffeine increases anxiety and restlessness, causes sleep disturbances, and increases urine flow. As these symptoms are often problems for clients with Alzheimer's Disease, it is recommended that caffeine-containing products be used in moderation, if at all.

As with other drugs, the careprovider should closely observe and monitor the client for side-effects or adverse effects and limit consumption accordingly.

If the client has difficulty sleeping, wakes up in the night to void, or experiences night-time incontinence, caffeine consumption may have to be restricted. Caffeine use can be limited to mornings only, or decaffeined coffee, tea, and colas can be substituted.

To The Coordinator

In the client assessment for service, inquire about the use of alcohol, nicotine, and caffeine. You may advise the family of the type of side-effects associated with the use of these drugs if they appear to be affecting the client.

Inform the careworker of the agreed-upon use of these agents and review what to observe.

It is important that the family be encouraged to follow these guidelines to ensure consistency and maximize client well-being.

Chapter 22
Recreational Activities

Daily life involves different types of activities: working; socializing with others; taking care of ourselves, our families, and our home; and participating in hobbies and sports. Activities give structure and meaning to our lives.

Involvement in activities is important at all ages and in all health conditions. Even when ill, there are activities that can and should be done by the client. Normal aging and disease may affect the choice of activity and the level at which the individual can participate.

Activities And Alzheimer's Disease

It is important that the cognitively impaired client remain involved in as many usual life activities as possible. Because of their impairments, clients may need assistance with some activities, or activities may have to be adjusted to the level of function.

Participation in recreational activities is an important part of the client's life and, as such, an important aspect of the careworker's role.

Recreational Activities

Recreational or leisure activities are usually chosen for enjoyment. They are pleasant to do and contribute to the participant's sense of well-being and satisfaction.

The client gains much from being involved in recreational activities, which:

- provide stimulation and prevent boredom;
- help maintain physical and cognitive function and social skills;
- help meet psychological needs by providing a way of being involved with others, "doing something," having some control, and maintaining a sense of independence;
- increase feelings of happiness, satisfaction, and well-being;
- provide a sense of feeling "useful"; and
- serve as a connection with his/her earlier life.

Training Points

It is important for the careworker to follow the Client Care Guidelines (Chapter 10, BASIC PRINCIPLES). Points to reinforce in training include:

- Find out from the client and his/her family about past/present interests, skills, and hobbies that may be useful in identifying activities for the client to do now.
- Observe the client to know his/her level of function, capabilities, and limitations.
- Involve the client as much as possible in the usual activities of life.
- Provide just the right amount of assistance. Find the right balance.
- Allow and encourage the client to do as much as possible independently.
- Try not to let the client feel frustrated. Do not challenge clients with tasks they can no longer perform.
- Ensure that client safety and well-being are maintained.

Meaningful Activities

Meaningful activities are ones that have a purpose or goal and are recognized by the client as being worthwhile. Meaningful activities encourage growth and accomplishment and reinforce and enhance client self-esteem.

Activities that only "fill time" and are used to "keep busy" are not as fulfilling, even to the cognitively impaired individual.

Considerations In Choosing Activities

To be successful, activities selected must take into consideration the client's present condition (cognitive and physical function, emotional status), and past interests (hobbies and skills). Consideration must also be given to such other factors as cost and required material or space.

The careworker or coordinator may wish to discuss with the family the possibility of purchasing games or other materials for the client. As well, the agency may consider providing, on a loan basis or at subsidized cost, recreational materials for use by the client under the supervision of the careworker.

Modifying Activities To The Client

The careworker's ingenuity and intuitiveness will be useful in adapting recreational activities to the client's capabilities. As always, it is important to treat the client with respect and in an adult manner. If an activity causes more frustration than pleasure, even when modified, it may have to be discontinued.

Types Of Recreational Activities

A list of recreational activities appropriate for the cognitively impaired client is provided at the end of this chapter. Specific careworker guidelines and suggestions are found in Chapter 14 of BASIC PRINCIPLES (Recreational Activities).

Additional suggestions for recreational activities are available in the book *Doing Things*, by J.M. Zgola (see bibliography at the end of this manual).

Levels Of Participation

Participation can be satisfying at many different levels. The individual who is too cognitively impaired to participate directly in an activity may still derive pleasure from watching, which gives the client a sense of belonging and involvement.

Dealing With Specific Problems

This section reviews three typical problems encountered with the cognitively impaired client and provides suggestions for the careworker.

Dealing With "Refusal"

Some clients will often say "no" when asked if they would like to do something.

Often the refusal is because the client does not understand, has forgotten, or is afraid of not being able to perform the activity. Some clients may just need help getting started.

By knowing and carefully observing the client, the careworker will have a good idea about the likelihood of the client's ability to perform the required tasks and will be able to anticipate the type of assistance or modification required.

It is essential to follow the Client Care Guidelines.

Guidelines For The Careworker To Help Overcome Client Refusal

- Choose a time of day when the client functions best.
- Make a direct statement. Do not give options that may only confuse the client. Say: "Let's paint." Not: "Would you like to paint?"
- It is helpful to show the client the paints and paper. That will help remind the client.
- Involve the client directly. Ask the client to hold the brush, or place the brush in the client's hand.
- Give the client a reason for doing the painting: "This painting will be a nice present for your wife."
- Help the client get started. Step-by-step, guide the client through the activity. Give one-step-at-a-time instructions. Repeat verbal instructions. Demonstrate new tasks. Place your hand over the client's and go through the motion.
- Stay calm and relaxed.
- Stay with the client. Give encouragement. Praise efforts and achievements sincerely.
- You may try again another day, perhaps modifying the activity. If the client's condition has deteriorated markedly, the activity may have to be abandoned.
- Do not force the client to do an activity that he/she really does not want to do.
- Use the problem-solving approach to determine what is causing the difficulty; then take the appropriate action.

- Check out all the possible interfering factors in the client (physical, cognitive, emotional); in the environment (too noisy, too many distractions); in yourself (are you rushed? anxious? annoyed?).
- When previously enjoyed activities can no longer be performed, look for new activities that are within the client's functional ability.

Short Attention Span

Cognitively impaired clients have a short attention span and have difficulty focusing their attention. Activity length will depend on the individual's cognitive function. In the mild to moderate stages, activities ranging from 15 to 30 minutes are usually tolerated.

Perseveration (Excessive Repetition)

Motions that are repeated over and over are easiest for the cognitively impaired client to perform. The client will continue the same motion (e.g., wiping a dish, sanding a board) until stopped by something/someone else. Most perseverated activities are harmless. When you see signs of client stress, divert the client to something else.

Case Study Using The Problem-Solving Approach

The following case study is presented to demonstrate the use of the problem-solving approach in analyzing an activity and adapting it to the client's level of function and interests.

Background

Mrs. D. is a 71-year-old woman who has enjoyed baking for her family. She is considered to be in the middle stage of Alzheimer's Disease and requires supervision because of her confusion. Mary, her careworker, has worked with Mrs. D. for the past 14 months.

Client Assessment

Physical Condition

- weak;
- poor eyesight;
- arthritic fingers, joints stiff;
- has difficulty grasping objects, particularly thin objects such as forks.

Cognitive Function

- poor memory, careworker must repeat instructions;
- often confused and disoriented, particularly in unfamiliar surroundings;
- understands simple instructions.

Emotional State

- usually happy and content;
- happiest when doing familiar household tasks.

Interests

- past—enjoyed cooking and baking for her family;
- present—likes helping in food preparation.

Other Motivating Factor At This Time

- her granddaughter is coming to visit tomorrow;
- the granddaughter likes chocolate chip cookies;
- Mrs. D. would like to bake cookies for her granddaughter's visit.

Baking Cookies — Breakdown Of Tasks

Task	Associated Skills
Read the recipe.	• Sight (reading directions) • Understanding (following directions)
Assemble the ingredients.	• Memory (where are ingredients stored?)
Measure the ingredients.	• Strength (reaching and carrying) • Sight (reading the measurements) • Coordination (pouring ingredients)
Mix the batter.	• Strength • Coordination
Transfer the batter to the cookie tray.	• Coordination • Repetitive action
Turn on the oven.	• Sight
Put the cookie tray into the oven to bake.	• Strength • Coordination
Watch the time to know when cookies are ready.	• Memory • Sight/hearing (to note timer)
Remove tray from oven.	• Strength • Coordination

Task	Associated Skills
Remove cookies from tray and put them in cookie tin.	• Using a lifter • Repetitive action
Clean up (a separate activity made up of many tasks requiring a variety of skills).	

Analysis

On reviewing her assessment of Mrs. D. and considering the tasks involved in baking, Mary decides that baking cookies would be a good activity for Mrs. D. Mrs. D. will be very happy and proud to greet her granddaughter with a fresh batch of cookies.

Activity Modification And Adaptation

Mary considers how she might provide assistance so that Mrs. D. will be able to do as much of the baking as she can. Mary knows that she will have to observe Mrs. D. and make further changes in her plan, depending on how Mrs. D. is managing.

Mary decides, based on her experience with Mrs. D., that it is best if Mary assembles the ingredients and utensils and puts them out in the order they are needed.

Mrs. D. has no trouble measuring the flour and sugar. One at a time, Mary calls out the names of the ingredients, tells Mrs. D. how much to measure, and reminds her to put the ingredient in the mixing bowl when she forgets.

Mary knows Mrs. D. has trouble pouring milk from the pitcher, so she premeasures the milk. Mrs. D. gets confused with the other ingredients, so Mary measures them and has Mrs. D. add them to the bowl, one at a time.

Mrs. D. should have no trouble stirring the batter with a large wooden spoon. When the ingredients are in the bowl, Mary tells Mrs. D. to pick up the spoon and then to stir the batter. At first, Mrs. D. is confused, so Mary makes a mixing motion in the air with the spoon. Mrs. D. remembers and stirs the batter until it is all mixed.

Mary turns on the oven to preheat it.

When the batter is mixed, Mary remarks on the fine consistency of the batter and how well Mrs. D. has mixed it.

Mary then tells Mrs. D. to drop the cookie dough onto the tray. Mrs. D. looks confused. Mary realizes Mrs. D. has forgotten how. Mary knows Mrs. D. likes to do things herself and just needs reminders when baking. Mary stops for a moment to think of the specific steps in transferring the dough from the bowl onto the cookie tray. Relaxed and calm, Mary proceeds to give instructions for each step. She repeats the instruction as often as necessary, waiting until the task is completed before going to the next step:

- Pick up the teaspoon.
- Dip the spoon into the batter.
- Fill the spoon with batter.

- Move the spoon over to the tray.
- Slide the dough onto the tray.
- Put more batter on the spoon...and repeat.

After Mary guides Mrs. D. over the procedure a few times, she notices that Mrs. D. is working more quickly and no longer needs reminders. When the tray is filled, Mary replaces it with an empty one. For a moment, Mrs. D. is confused by the empty tray, but Mary repeats the instructions and Mrs. D. continues placing the cookie dough on the tray until it is filled.

Mary praises the neat rows of cookies that Mrs. D. is arranging. When the tray is full, Mary repeats, "What a nice treat the cookies will be for your granddaughter."

Mary puts the trays in the oven. She sees that Mrs. D. is tired, so she suggests Mrs. D. sit down after her hard work and rest while the cookies bake.

Mary cleans up the kitchen. She periodically comes over to Mrs. D., gives her a reassuring hug or touch, and remarks on how good the cookies smell. The two women talk about how pleased the granddaughter will be.

When the cookies are ready, Mary takes them out of the oven, praising how good they look and smell. When the cookies cool off, Mrs. D. has no trouble placing them in the cookie jar.

Mrs. D. and Mary enjoy a cookie and a cup of tea as a reward for their efforts.

Evaluation

Mary observes how proud and happy Mrs. D. was baking the cookies. She decides that she will plan regular baking and cooking activities with Mrs. D.

The Skills Used

Activity adaptation uses the careworker's skills of observing, problem-solving, and communication.

A Rewarding Experience

One of the benefits of successfully involving the client in a meaningful activity is the satisfaction of knowing you help him/her achieve a sense of pride, enjoyment, and self-esteem.

Checklist Of Recreational Activities

The following checklist includes a broad variety of suggestions. Careworkers should, of course, be encouraged to expand on the list.

Checklist Of Recreational Activities

Social Activities	• Conversation • Reminiscing (may look at photographs from the client's past)
Reading	• Reading may be enjoyed for some time after conversational ability is impaired
Crafts	• Bead work • Ceramics • Drawing or painting (crayons or water colors) • Macramé • Rug hooking
Games	• Card games (match numbers, colors, suits) • Bingo • Simple board games • Dominoes
Exercise	• Walking • Stretching • Dancercise • Aerobics • Bowling • Swimming • Fishing
Music	• Listening to music • Singing • Dancing • Playing musical instruments
Visual	• Looking at photographs from the past • Looking at magazines (pictures) • Watching television • Watching others as they work or perform tasks
Gardening	• Watering plants, grass • Raking leaves, grass

Outings	• Shopping • Visiting relatives/friends • Going to a park or other recreational area
Household Activities These can be related to previous work or to hobbies enjoyed prior to the illness. A homemaker may still participate in a number of household tasks.	• Cooking (washing and chopping vegetables, adding ingredients to pot, stirring, mixing ingredients) • Dusting • Sweeping • Dish-washing or drying • Setting the table • Making beds • Folding laundry • Watering plants • Knitting, crocheting, darning • Polishing silver, brass, furniture • Woodworking • Painting • Gardening

Summary

With appropriate assistance, cognitively impaired clients should participate to the full extent they are able in the usual activities of life. Such participation plays an essential role in maintaining one's quality of life.

Chapter 23
A Safe Home Environment

The home environment, which is particularly important for the cognitively impaired client, requires the careworker's special attention. Care should be taken to ensure that surroundings are safe and easily managed.

Anything that may be dangerous to the client or confusing, upsetting, or distracting should be removed. Some clients, no longer recognizing even their own image, are frightened by mirrors. For those with failing vision, objects may appear distorted and become easily misinterpreted.

It is important that the home setting be a familiar place. During the client assessment the coordinator should inspect the home and offer appropriate suggestions to the family. Consultation with an occupational therapist may be required to ensure the home is set up in a way that will enable the client to function best.

Accommodating Memory Impairment

Predictability is essential, and it is important to avoid clutter and keep everything in its own place. Modifications to the home may be required to ensure that surroundings are safe, secure, and adapted where possible to the client's functional capacity. The result will be a setting that allows the client to participate in usual home routines.

The Home Setting

The client's surroundings should be set up:

- to promote and ensure client safety;
- to maintain consistency, predictability, and familiarity;
- to accommodate and compensate for the client's physical and cognitive deficits;
- to minimize confusion; and
- to reduce excessive and unnecessary stimuli (visual and auditory).

Consultation With An Occupational Therapist

An occupational therapist may be consulted to assess the client and the home and to make recommendations for specific changes. In some cases, financial assistance is available for assistive devices and modifications.

The Importance Of Continuity By The Family

Home modifications require the family's consent, cooperation, and active participation. The coordinator should make suggestions and review the following list at the time of the initial assessment and whenever alerted to a problem. The careworker should be encouraged to discuss with the family the types of modifications available and to alert the supervisor to the need for consultation with an occupational therapist.

The following Home Safety Guidelines and Checklist, to be reviewed with the family and the careworker, identifies areas that require special attention to ensure that the home is safe and manageable for the client.

Home Safety Guidelines And Checklist

Supervision

- Do not leave clients alone in the home when they are disoriented, unable to manage alone, or if you have been instructed to remain with them.

Fire Protection

- Ensure that matches or inflammable materials are safely locked away.
- Stay with the client when he/she is smoking.
- Make sure there are smoke detectors located throughout the house. Make sure they are operating properly.

Accident Protection

Watch For Hazards That Can Cause Accidents

- Ensure scatter rugs are secured to the floor.
- Keep clutter out of the way so client can move about easily.
- Make sure there are no wires or cords to trip over.
- Check that space heaters and fans are securely fastened and in good repair.
- Ensure there is adequate lighting in rooms and hallways.
- Make sure floors are not slippery — wipe up spills promptly.
- Remove dangerous objects (knives and other sharp objects).
- Install railings on stairways and in long corridors.
- Put safety locks on outside doors and windows.
- Make sure there are clear contrasts in color so the client can see the edge of stairs, doorways, and the bottom of the bathtub.

Room Check

Kitchen

- Make sure there is a safety switch to prevent the client from leaving on stoves, kettles, and other electrical appliances.
- Lock up, or store safely out of reach, knives or other potentially dangerous implements.
- Store cleaning solutions, other chemicals, and other poisonous materials securely out of reach.
- Keep medications, including over-the-counter health-related products, securely locked away.
- Clear the kitchen of inedible items that the client may mistake for "food" and try to eat.
- Use unbreakable dishes and glasses for the client.

Bathroom

- Make sure the hot water setting is lowered to prevent accidental scalds or burns.
- Use nonskid mats in the tub and on the floor.
- If required, install grab bars and special hand grips in the tub and at the toilet.
- Use plastic or other unbreakable items in the bathroom.
- Remove the lock from the bathroom door.
- Leave on night-lights in and leading to the bathroom.
- Use colored decals or mats in the bathub so that the client can see the bottom of the tub.

Bedroom

- Avoid clutter.
- Keep the set-up familiar — do not change or rearrange furniture.
- Leave on a night-light.
- Secure rugs to the floor.
- Remove potentially dangerous objects.
- Lock drawers or cupboards containing valuable or potentially dangerous items.

General

- The atmosphere should be calm, relaxed, pleasant, and accepting.
- Follow a routine familiar to the client.
- Ensure adequate light, heat, moisture (not too dry or damp).

- Leave on night-lights, especially in and leading to the bathroom.
- Use calendars, signs, labels, and clocks as reminders and to orient the client.

Avoid Clutter

- Do not leave unnecessary objects around.
- Remove excess furniture.
- Make sure there is sufficient open space in the rooms so the client can walk around easily without bumping into furniture.

Avoid Excess Stimuli

- Avoid excessive noise, distracting lights, crowds of people, and general hustle and bustle.

Ensure Use Of Prescribed Assistive Devices

- Make sure the client is using prescribed personal assistive devices appropriately and that they are properly adjusted and functioning:
  - dentures (false teeth)
  - eyeglasses
  - hearing aids
  - canes
  - walkers
  - artificial limbs
  - braces
  - supports
  - special footwear
  - other personal devices

Other

- Mirrors may have to be removed or covered when clients no longer recognize themselves and become confused or scared by the image.
- Avoid sharp edges on furniture to prevent injury if accidentally bumped into.
- Avoid busy prints or patterns on furnishings or wall hangings.
- Make signs with black or dark colors on a light background (white or yellow backgrounds are easiest for the elderly to interpret).
- Lock drawers or cupboards that contain potentially harmful items or objects known to result in problems.

Summary

This chapter on home safety ties together many of the pointers presented in this manual. Commonsense, patience, sensitivity, and caring are vital factors in good care.

Part V

Training Program

Chapter 24
Training Program

This chapter, which presents suggestions related to the implementation of the careworker training program, is divided into three main sections.

The first section, "Curriculum," deals with the content of the training portion of the manual and includes related exercises. The second section, "Suggestions For Presentation, Discussion, And Exercises," offers the coordinator a variety of tips on the presentation of the program and also includes exercises. The third section, "Suggestions For Evaluation," offers suggestions to assist in the evaluation of the careworker. A sample short-answer test and true-or-false quiz are included.

For additional suggestions in training and for sample handout materials, the coordinator is referred to *In-Home Respite Care For Older Adults*, edited by S. Klein (see bibliography).

Curriculum

I Introduction

Part I provides an overview of:

- normal aging — age changes and their impact on the elderly individual;
- dementia — reversible and irreversible;
- cognitive impairment;
- Alzheimer's Disease and the effect on the client and family; and
- a problem-solving approach to client care.

Objectives

- To provide the careworker with a general understanding of these issues as they relate to client care.
- To emphasize practical considerations and techniques that may be helpful to the client in adjusting to or accommodating changes.
- To prepare the careworker for what to expect with the client.
- To sensitize the careworker to what the client and family may be experiencing.

Discussion Ideas And Exercises For Careworker

1. Discuss some of the common myths about aging.
2. Describe a situation with an elderly individual (may be a client or from a personal situation) in which, to improve his/her function, you made allowances for an impairment or other disability.
3. Brainstorm ideas that can be used to overcome or help with normal-aging disabilities.
4. a. What are the basic physical needs of life?
   b. What are the psychological needs?
   c. What emotional reactions may result from unmet physical or psychological needs?
5. Review the following case study and answer the questions that follow it.

   > Mrs. W. is a 76-year-old widow who has suffered from memory loss and confusion for the past two years. She has lived alone since her husband died eight years ago. Her daughter, who lives 200 km away, recently came to visit and found that the house was quite untidy, there was no food in the refrigerator, and her mother seemed quite anxious. The daughter made arrangements with the agency to have a careworker go to her mother three afternoons a week.

   a. What needs of the mother are unmet?
   b. What can happen if those needs are not met?
   c. What can a careworker do to help Mrs. W. meet her needs?
6. Imagine how you would feel if your mother had Alzheimer's Disease and you were no longer able to provide all her care. What would you be concerned about when looking for someone to help care for her? How would a careworker show you that she is competent to care for your mother?

Resources

Show a short introductory film or video that is designed to sensitize and provide the viewer with an overview of Alzheimer's Disease and related disorders.

II Careworker's Role

Part II includes a discussion on the role and place of the careworker in the respite care team:

- the role and responsibility of the careworker;
- respite care;
- the team approach;
- building a trusting relationship; and
- problems that may be encountered with client and family, and how to deal with them.

Objectives

- To define the role and place of the careworker in the overall care program.
- To emphasize the importance of the careworker role.
- To instil a sense of pride in the careworker.
- To enhance a sense of responsibility and commitment in the careworker.

Discussion Ideas And Exercises For Careworker

1. Discuss the attributes and characteristics of a professional careworker.
2. Relate incidents on how you gained the trust and established a good rapport with initially difficult family members.
3. Brainstorm ideas on how to gain client trust and family trust.
4. In order to help people, it is helpful to get to know what they are experiencing — their feelings, needs, values, beliefs, and interests. The situation may be very difficult with the Alzheimer's client because he/she has difficulty communicating effectively. You will have to use your communication skills to interpret the message he/she is trying to send you.

   It would be helpful if you put yourself "in his/her shoes." How would you feel if you realized something was wrong with you, that simple tasks confused and overwhelmed you, and you couldn't remember people, or even your way home?

   How would you feel if you saw a close relative deteriorating to the point that he/she no longer could eat or dress without help, or even recognized you? The many personal losses, the complex emotional reactions, and the physical burdens of care are overwhelming. The reality that the situation will only get worse is devastating. What help would you like in such a situation? How would you want a careworker to act with you and with your close family member?
5. With which members of the care team does the careworker work the most?
6. What is the careworker's responsibility to the other team members?
7. What skills does the careworker need in order to work as an effective team member?
8. What can happen if a team member does not perform his/her duties appropriately? What do you see as the benefit of the team approach?
9. Review the following case study. As the careworker, what would you do?

   Mr. R. is an 81-year-old man suspected of suffering from Alzheimer's Disease. He lives with his 76-year-old wife, who has severe arthritis in her hands and knees. The careworker has noticed that Mr. R., who usually has a good appetite, has been refusing to eat any solid food. He appears more restless than usual, and has been yelling at his wife. Mrs. R., usually quite talkative, does not appear even to hear him.

III Special Skills

Part III reviews the skills required by the respite careworker, which include:

- problem-solving and decision-making;
- observing and reporting;
- communication; and
- stress management (related to overinvolvement, burnout, dealing with a dying client).

Objectives

- To provide the careworker with the basic skills required.
- To ensure the careworker understands what is expected in this role.
- To prepare the careworker.
- To reinforce the responsible nature of the position.
- To instil a sense of importance and pride in work.

Discussion Ideas And Exercises For Careworker

1. Review:
   a. the importance of following a systematic process in problem-solving;
   b. the importance of using skills of observation;
   c. the importance of keeping accurate records and of reporting;
   d. the importance of communication;
   e. the importance of careworkers taking care of themselves.

2. Mrs. R. is a 71-year-old housewife who suffers from Alzheimer's Disease. In helping her bathe, you notice she has a skin lesion on her left shin. It is three inches in diameter and is oozing a fluid. What would you do?

3. Mr. T., a long-time client who is in early middle stage of Alzheimer's Disease, has been calling for his mother (who is long dead) all afternoon. What would you say to him?

4. Give suggestions from experience, reading, or training on ways to promote communication with the client in early and middle stages.

5. Come up with examples of "body language," and list them on a flip chart.

Resources

Video: ***The Best They Can Be: Communicating With People Who Have Alzheimer's Disease.***

IV Client Care

Topics presented in Part IV include:

- client care guidelines;
- behavior management;
- personal care activities (hygiene, dressing, eating, toileting, handling medications); and
- recreational activities.

Objectives

- To prepare and familiarize the careworker for situations that she may encounter.
- To provide the careworker with guidelines and strategies on how to manage care situations.
- To reinforce to the careworker the importance of considering the many diverse factors that can influence client behavior.
- To review the range of services required in care.
- To reinforce:
  - the problem-solving approach,
  - the importance of observation and reporting,
  - the importance of ongoing communication with the client,
  - the responsibility of the careworker's role, and
  - the importance of maximizing the client's involvement in all activities, to the extent able.

Discussion Ideas And Exercises For Careworker

1. Discuss General Client Care Guidelines. Explain the reason(s) behind each guideline.
2. Discuss why the clients may display problem behaviors. (The coordinator should emphasize that unusual behaviors are part of the disease, not in the client's control and not to be taken personally.)
3. Discuss the importance for everyone of involvement in activities (personal gains, social gains). Then discuss the importance of keeping Alzheimer's clients involved in as many life activities as possible.
4. Discuss particular problems related to client behavior. How did you handle them? How would you handle them now?

Resources

Video: ***Building Upon The Strengths: Alzheimer's Disease And The Activities Of Daily Living.***

Suggestions For Presentation, Discussion, And Exercises

1. Encourage the participation of each careworker.
2. Build on the material presented in each part of the curriculum. Relate the new information to the information presented earlier. (For example, relate behavior and activities management to the aging process, the disease state, and the skills presented.)
3. Invite the careworkers to present case examples based on their experience.
4. End each section by summarizing the main points. It may be helpful to write the points on a flip chart or blackboard.
5. You may have summary points distributed to the careworkers following the sessions, or you may have the careworkers take their own notes.
6. It is often helpful to use role-play techniques. One careworker takes the role of the client and another "manages" the situation. Such techniques are useful for demonstrating ways of managing difficult behavior and performing the activities of daily life.
7. Relate teaching and principles as much as possible to the careworkers' experiences. Workers new to the profession may draw on personal examples, such as caring for grandparents or elderly friends or neighbors.
8. Select and show appropriate videos or films available from the Alzheimer's Society, the public health department, or the public library.
9. Encourage careworkers to read and refer to *Basic Principles: A Careguide For Careworkers Providing In-home Care To Clients Suffering From Alzheimer's Disease And Related Disorders.*
10. Inform careworkers of other helpful references such as: *The 36-Hour Day, A Family Guide to Caring for Persons with Alzheimer's Disease, Related Dementing Illnesses, and Memory Loss in Later Life*, by Nancy L. Mace and Peter V. Rabins.

Suggestions For Evaluation

Evaluation of acquired knowledge is an integral part of any training program. Some techniques that may be used for evaluation purposes are presented for your consideration. Evaluation generally is based on:

1. Participation in class discussions.
2. An interview-type oral exam.
3. A "formalized" written or practical test.

Given the uniqueness of the carework situation, evaluation based on participation in the training process, along with an informal oral review, may be preferable to a more formalized written test.

The trainer/supervisor can direct questions to individual careworkers in a non-threatening manner during the course of discussions. It is important that the supervisor record participation and knowledge immediately at the end of each training session.

The nature of the work requires commonsense, a calm manner, and the ability to problem-solve. An interview-type oral review, using a situation/response format and administered by the supervisor on a one-to-one basis, may be an effective method of assessing worker knowledge. This method is important in cases where there might be a language barrier.

If a formalized written test is required, facts may be assessed using true or false or short-answer questions. This technique may be very useful to assess Part I of the curriculum (Normal Aging and Dementia). Sample questionnaires are provided.

Certificate

On completion of the training program, the careworker may be provided with a certificate from the agency acknowledging participation in the initial training program.

Sample Written Test

Short Answer

1. Describe six normal-aging changes.
2. What could be used to help a client who has trouble seeing?
3. What is cognitive impairment?
4. Briefly describe how the client appears during the three stages of Alzheimer's Disease.
5. Briefly describe what the client experiences during the three stages of Alzheimer's Disease.
6. What is respite care?
7. Who benefits from respite care?
8. What are three nonphysical needs of all people?
9. Give three examples of nonverbal communication?
10. Why is it important for clients with Alzheimer's Disease to do as much as they are able for themselves?
11. What are the levels of assistance (from least to most) that a careworker may have to give to an Alzheimer's client to help perform an activity?
12. What activities would be appropriate for a middle-stage Alzheimer's client who was a homemaker and had raised a family?
13. What would you do if the client insisted on going out for a walk?

14. If a 79-year-old client called out for his mother, what might that indicate? How would you respond?
15. Why is it important not to give a client with Alzheimer's Disease medications that were not prescribed specifically for his/her use?
16. What would you do if a client accused you of "stealing" her purse?
17. What would you do if a male client grabbed your bottom while you were bathing him?
18. What senses do you use when "observing"?
19. If a cognitively impaired person was having trouble eating with a fork, what would you do?
20. If the family member asks you to do something that you feel is not your job, what would you do?

True/False

1. The course of Alzheimer's Disease is predictable.
2. All old people have memory problems.
3. The client should always be treated with respect and dignity.
4. It is best to take over and do everything for a client who is cognitively impaired.
5. Predictable routines are easiest for the cognitively impaired to follow.
6. Client safety is the first concern.
7. The cognitively impaired person does not need to participate in activities.
8. Respite means "relief."
9. Teamwork is not important in the care of the cognitively impaired.
10. The family caregiver needs a break from the responsibility of providing continuous care.
11. Alzheimer's clients have no feelings.
12. Redirecting the client's attention from problem situations can be helpful.
13. Providing a snack, such as juice or cookies, is an example of a diversion.
14. The careworker can promote a sense of control and self-esteem in the client by allowing the client to make a choice, such as between wearing a red shirt or a blue sweater.
15. It is important for the careworker to act in a calm and relaxed manner at all times.
16. There is a meaning behind most behaviors.
17. Nonverbal communication is not important with the cognitively impaired.
18. It is important to look for a cause or causes when the client's behavior changes suddenly.

19. Clients with Alzheimer's Disease are sensitive to the mood and behavior of those caring for them.

20. Involvement with others and with activities is important for clients with Alzheimer's Disease.

Bibliography

Aronson, M.K. (editor). *Understanding Alzheimer's Disease: What It Is/How To Cope With It.* Toronto: Collier Macmillan Canada, 1988.

Barton, D. (editor). *Dying And Death: A Clinical Guide For Caregivers.* Baltimore: Williams & Wilkins, 1977.

Baycrest Centre For Geriatric Care. "Cognitive Impairment: Helping Families Cope — The Social Worker's Role." Conference Proceedings, Social Work Clinic Day, 1981.

Canada's Food Guide.

Cohen, D., and C. Eisdorfer. *The Loss of Self: A Family Resource For The Care Of Alzheimer's Disease And Related Disorders.* New York: New American Library, 1986.

Conahan, J. *Helping Your Elderly Patients: A Guide For Nursing Assistants.* New York: The Tiresias Press, 1976.

Coons, D.H., et al. (editors). *A Better Life: Helping Family Members, Volunteers And Staff Improve The Quality Of Life Of Nursing Home Residents Suffering From Alzheimer's Disease And Related Disorders.* Columbus, Ohio: The Source, 1986.

Cormack, Desmond (editor). *Geriatric Nursing: A Conceptual Approach.* Blackwell Scientific Publications, 1985.

Crepeau, E.L. *Activity Programming for the Elderly.* Boston: Little, Brown, 1986.

DuFresne, F. *Home Care: An Alternative To The Nursing Home.* Elgin, Ill.: The Brethren Press, 1983.

Edelson, J.S., and W.H. Lyons. *Institutional Care Of The Mentally Impaired Elderly.* New York: Van Nostrand Reinhold, 1985.

Feil, N. *Validation: The Feil Method — How To Help Disoriented Old-Old.* Ohio: Edward Feil Productions, 1982.

Gwyther, L.P. *Care Of Alzheimer's Patients: A Manual For Nursing Home Staff.* American Health Care Association; Alzheimer's Disease And Related Disorders Association. New York: Van Nostrand Reinhold, 1985.

Hanmer, H. *A Report On Alzheimer's Disease.* Toronto: Ontario Council on Senior Citizens, 1986.

Hastings, D. *The Complete Guide To Home Nursing.* New York: Barron's Educational Series, 1986.

Henig, R.M. *The Myth of Senility: The Truth About The Brain And Aging.* Washington, D.C.: AARP, 1985.

Heston, L.L., and J.A. White. *Dementia: A Practical Guide To Alzheimer's Disease And Related Illnesses.* New York: W.H. Freeman, 1983.

Hills Maguire, G. (editor). *Care Of The Elderly: A Health Team Approach.* Boston: Little, Brown, 1985.

Hooyman, N.R., and W. Lustbader. *Taking Care: Supporting Older People And Their Families.* New York: The Free Press, 1986.

Horne, J. *Care-Giving, Helping An Aging Loved One.* Washington, D.C.: AARP, 1985.

Kahn, R., E Shulman, and G. Steinberg. *How To Care For The Alzheimer's Disease Patient: A Comprehensive Training Manual For Homemaker-Home Health Aides.* The Foundation For Hospice And Homecare, 1986.

Klein, S. (editor). *In-Home Respite Care For Older Adults.* Springfield, Ill.: Charles C. Thomas, 1986.

Mace, N.L., and P. Rabins. *The 36-Hour Day: A Family Guide To Caring For Persons With Alzheimer's Disease, Related Dementing Illnesses, and Memory Loss In Later Life.* Baltimore: Johns Hopkins University Press, 1981.

McDowell, F. (editor). *Managing The Person With Intellectual Loss (Dementia Or Alzheimer's Disease) At Home.* The Burke Rehabilitation Centre, 1980.

Nursing Clinics of North America. *Alzheimer's Disease And Urinary Incontinence In The Elderly.* Vol. 23, No. 1. Philadelphia: Saunders, March 1988.

Obler, L.K., and M.L. Alber. *Language And Communication In The Elderly.* Lexington Books, 1980.

Ontario Association Of Homes For The Aged. *Guide To Caring For The Mentally Impaired Elderly.* Toronto: Methuen, 1985.

Ostunti, E., and M.J. Santo Pietro. *Getting Through: Communicating When Someone You Care For Has Alzheimer's Disease.* New Jersey: The Speech Bin, 1986.

Powell, L.S., and K. Courtice. *Alzheimer's Disease: A Guide For Families.* Reading, Mass.: Addison-Wesley, 1986.

Reisberg, B. *A Guide To Alzheimer's Disease, For Families, Spouses And Friends.* New York: The Free Press, 1981.

Ross, M. *The Silent Epidemic: A Comprehensive Guide To Alzheimer's Disease.* Hounslow Press, 1987.

Simonson, W. *Medications And The Elderly: A Guide For Promoting Proper Use.* Aspen Systems Corporation, 1984.

Statistics Canada. *The Seniors Boom.* Ottawa: October 1986.

Tanner, F., and S. Shaw. *Caring: A Family Guide To Managing The Alzheimer's Patient At Home.* New York: Publication of the New York City Alzheimer's Resource Center, July 1985.

Thompson, W. *Aging Is A Family Affair: A Guide To Quality Visiting, Long-Term Care Facilities And You.* Toronto: NC Press, 1987.

Wolanin, M.O., and L.R.F. Phillips. *Confusion: Prevention And Care.* Mosby, 1981.

Zgola, J.M. *Doing Things: A Guide To Programing Activities For Persons With Alzheimer's Disease And Related Disorders:* Baltimore: Johns Hopkins University Press, 1987.

Zucker, E. *Being A Homemaker/Home Health Aide.* Elora, Ont.: Robert J. Brady, 1982 (Directional Learning, 480 Washington St., Elora, Ont. N0B 1S0).

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Additional resources for the coordinator, careworker, and family may be obtained from local chapters of the Alzheimer Society; the Ministry of Community and Social Services, Province of Ontario; public health units; and psychogeriatric units of local hospitals.